

The Impact of Specialist Seating on a Person's Quality of Life and Functional Abilities

Hannah Shelstone

23038436

Word count: 15,130

By submitting this work:

I confirm that all service user and personnel names used in this work are pseudonyms and the identity of the service, service users, carers and staff has been protected.

I confirm that the work submitted is my own and that I have identified and acknowledged all the sources used as part of my submission.

CONTENTS

Abstract.....	3
Acknowledgements.....	4
Background.....	5
The Importance of Good Posture.....	5
The Importance of Good Seating.....	6
Tilt-in-Space Seating.....	8
Literature Review.....	10
Tilt-in-Space and Pressure.....	10
Tilt-in-Space and Other Benefits	12
Primary Research Aim.....	17
Methodology.....	18
Study Design.....	18
<i>Research Method</i>	19
<i>Development of Interview Schedule</i>	21
Participants.....	21
<i>Inclusion Criteria</i>	22
<i>Exclusion Criteria</i>	22
<i>Sample Size</i>	23
<i>Method of Recruitment</i>	23
Procedure.....	24
Ethical Considerations.....	26
<i>Consent & Anonymity</i>	27
Data Analysis.....	28
Results.....	30
Quality of Life.....	31
<i>Comfort and Pain Relief</i>	31
<i>Fatigue Management and Aiding Rest</i>	32
Functional Abilities.....	34
<i>Activities</i>	34
<i>Independence</i>	35

Further Points of Interest.....	37
<i>Individuality</i>	37
<i>Funding</i>	39
Discussion.....	40
Quality of Life.....	40
<i>Comfort and Pain Relief</i>	40
<i>Fatigue Management and Aiding Rest</i>	43
Functional Abilities.....	46
<i>Activities</i>	46
<i>Independence</i>	48
Further Points of Interest.....	50
<i>Individuality</i>	50
<i>Funding</i>	51
Implications for Practice and Future Study.....	53
Strengths and Limitations.....	54
Conclusion.....	57
References.....	58
Appendices.....	63
1 – Confirmation of Collaboration.....	63
2 – Introductory Letter for Collaborators.....	64
3 – Researcher letter of Invitation.....	65
4 – Participant Information Sheet.....	66
5 – Participant Consent Form.....	69
6 – Interview Schedule.....	71
7 – Confirmation From SHU Dissertation Management Group.....	73
8 – NHS Research Ethical Committee Provisional Decision.....	74
9 – Covering letter to Ethical Committee Addressing Required Amendments..	80
10 – NHS Research Ethical Committee Final Approval.....	82
11 – NHS Research and Development Approval.....	85

ABSTRACT

A good posture is required in seating to provide a stable and balanced position from which activities can be completed independently, ensuring that the body is at the least risk of damage. When sitting with a poor posture, an imbalance of weight distribution can lead to the development of pressure ulcers and other severe physical complications, as well as impeding on function and communication and in turn impacting a person's quality of life and wellbeing. This means that individuals with diminished abilities to reposition to maintain a good posture due to muscle weakness and poor motor control require specialist seating to maintain an optimal sitting posture, reducing the likelihood of these complications developing. Tilt-in-space mechanisms have been developed in seating to provide postural alignment in order to offload pressure, provide a stable sitting position to improve function, relieve fatigue and maximise comfort for those with poor mobility and are therefore seated for many hours of the day. Research in this area has focused on tilt-in-space wheelchairs and understanding how and why the function is utilised for people living with severe disabilities as a result of a variety of conditions. The current study investigated, through qualitative semi-structured interviews, the impact of specialist seating on the quality of life and functional abilities for adults living with long term conditions or physical disabilities who were prescribed a tilt-in space armchair for the management of their condition and postural needs. Four participants were recruited from the case-load of a community occupational therapist working within a northern NHS Trust in England utilising a purposive sampling method. Data was analysed using Interpretive Phenomenological Analysis, identified as a suitable data analysis method for research exploring how individuals perceive their life experiences in terms of their health needs. The interviews revealed that all

participants found a different significant benefit of their tilt-in-space armchair in terms of comfort and pain relieving aspects, fatigue management and aiding rest, activity levels and independence. The bespoke nature of the chairs and funding issues were also important to highlight. The results have raised the awareness of the benefits of tilt-in-space seating for individuals with limited mobility as a result of a variety of conditions and disabilities, which occupational therapists need to consider when considering seating and positioning options.

Acknowledgements

The researcher would like to thank their research supervisor for their support, the occupational therapist who kindly acted as a gatekeeper and aided in the recruitment of the participants, and the participants themselves who agreed to spend time talking about their experiences.

BACKGROUND

The Importance of Good Posture

Posture regards the ability to stabilise different parts of the body relative to each other and the supporting surface, and being able to maintain this stability whilst re-arranging those body parts according to changing task demands and other forces (Pope 2007, in Long 2014). The basis of a good posture comes from symmetry and stability of the pelvis with pressure being transferred through the Ischial Tuberosities (the ‘sitting bones’ of the pelvis), which facilitates unhindered movement and allows for postural alterations to meet the task demands (Collins 2005, Long 2014). A good sitting posture allows a person to feel balanced and safe, reduces the effort of sitting, facilitates the completion of activities, supports independence, and puts the body at the least risk of damage (Hendrie 2009, CareFlex 2016). To sit in an optimum functional posture, a person needs good muscle tone and strength in order to maintain the position of the trunk against gravity (Lacoste 2003, Collins 2005). Typically people are able to alter their position to shift weight in response to discomfort if sitting for prolonged periods of time (many hours of the day), but this becomes more difficult for those with neurological conditions and/or physical disabilities, resulting in poor posture (Lacoste 2003, Collins 2005).

People with long term conditions, defined as “disease of, injury or damage to the body's nervous system” (Great Britain, Department of Health 2005 p13), experience a variety of physical problems associated with their condition. People with neurological conditions typically experience muscle weakness and impaired muscle tone which can impact motor control and mobility, resulting in an increasing difficulty to maintain postural control (Cook & Polgar 2015). Mobility and postural control are

also difficulties for individuals with musculoskeletal conditions who typically experience painful and stiff joints, muscle weakness, muscle wasting and fatigue (Cook & Polgar 2015). Postural management then becomes extremely important, as gravitational forces and neuromuscular impairment can damage soft tissues and change bony structures resulting in postural changes and deformities (Long 2014). This can in turn impair internal organ integrity leading to significant physiological changes in the cardiovascular, respiratory, abdominal, renal and neurological systems (Stewart 1991). Deteriorating mobility can also make it increasingly difficult to independently change position to shift pressure from weight-bearing surfaces in response to pain signals, leading to the development of pressure ulcers (Long 2014, Cook & Polgar 2015). A pressure ulcer is caused when pressure is applied externally and perpendicularly to a localised area of the body, depending on the magnitude and duration of the force (Cook & Polgar 2015). Frequently sitting with a poor posture can also lead to muscle shortening, pain, excessive muscle tightness, shaking, uncoordinated movements, communication difficulties, loss of balance, and it can result in a person being less able to carry out functional activities (Hendrie 2009).

The Importance of Good Seating

Clinical guidelines for the management of neurological conditions (such as Multiple Sclerosis) include ensuring a person's postural needs are accommodated appropriately by seating if they are at risk of developing postural abnormalities, are at risk of developing contractures which can impact on a person's ability to perform functional tasks, experience musculoskeletal pain or have swallowing difficulties (Multiple Sclerosis Society 2009). For people living with such conditions, the chair they sit in

can have a large impact on their life, so much so that “the quality of their chair determines the quality of their life” (Tierney 2012, p2). Good seating “provides a stable base, affords a proper biomechanical position, and is comfortable” (Cook & Polgar 2015, p197). If people sit for prolonged periods of time in a chair that does not promote a good sitting posture, existing physical and medical conditions can be exacerbated, and the physical complications that can occur as a result of postural abnormalities as mentioned above can reduce a person's quality of life and in severe cases be fatal (Tierney 2012, Tierney 2013, Long 2014). People with neurological conditions also become fatigued easily, and a poor seating position makes more demands on the body worsening this (Pope et al. 1988 in Dewey, Rice-Oxley & Dean 2004). Ordinary armchairs are therefore not suitable for people with complex requirements who are unable to maintain their posture or change position independently who sit for prolonged periods (Collins 2007). It is essential when prescribing alternative seating that the chair provides an appropriate posture for the person, as well as taking into account features such as pressure relief (Long 2014). By specifically tailoring a chair to meet an individual's current and future postural and pressure care needs for those who need to sit for prolonged periods of time but are not necessarily wheelchair dependent, seating can also enhance comfort, increase a person's activity related function, and improve their overall well-being (Collins 2005, Tierney 2012, Cook & Polgar 2015). Ordinary armchairs or recliners do not allow individuals to readjust their position or alter their posture to suit functional needs therefore the aims of specialist seating are to: reduce the possibility of abnormal postural changes, reduce pressure, ensure maximum stability for optimal function, provide comfort and promote independence (Collins 2007). Tilt-in-space seating has therefore been developed to address the discomfort, pain, pressure ulcers, spinal abnormalities, and loss of functional ability that sitting in the same position can result in (Lacoste 2003).

Tilt-in-Space Seating

In terms of preventing pressure ulcers for those who are sat for a long time, The National Pressure Ulcer Advisory Panel, European Pressure Ulcer Advisory Panel and Pan Pacific Pressure Injury Alliance (2014) state that a seated position needs to be adopted that minimises pressure and shear on an individual's skin, which can be done by providing tilt to prevent sliding. Tilt-in-space facilitates a person to sit in an L shape, maintaining flexion in the hips and knees at the optimal position of 90 degrees, ensuring pressure is distributed appropriately over the Ischial Tuberosities (Dewey, Rice-Oxley & Dean 2004). Tilting the seating backwards can also reduce the effects of gravity for those with low muscle tone and poor muscle strength, enabling them to maintain an optimal sitting posture and keep the trunk in midline which can relieve fatigue (Collins 2005, Cook & Polgar 2015). This postural alignment can enable even pressure distribution, reduce the likelihood of postural deformities developing, relieve back pain, increase stability, increase comfort, improve functional abilities, enable transfers, promote rest, potentially improve respiratory function and improve a person's overall quality of life (Cook & Polgar 2015, Lacoste 2003). According to Lacoste (2003), one of the most crucial aspects of successful specialist chair design is the degree of comfort it provides. The importance of seating may at first glance seem outside occupational therapy's remit; however its potential impact on functional abilities and therefore occupational performance, along with its role in improving quality of life, make it a clear consideration for the profession (Herzberg 1993, Reid, Brault & Croteau 2009).

Traditionally tilt-in-space has been utilised in wheelchairs, however armchair tilt-in-space seating systems have been developed for adults who experience difficulties with their mobility as a result of a neurological condition or physical disability who are

not necessarily wheelchair dependent. Tilt-in-space could therefore still be an important feature to ensure correct posture is maintained, ensuring management of their condition and promoting independence, potentially impacting on quality of life and functional abilities. Therefore this was the focus of the current study. A review of existing studies was carried out to identify what previous research had discovered regarding the benefits of tilt-in-space seating for adults with restricted mobility due to a variety of conditions.

LITERATURE REVIEW

A review of the literature was conducted utilising CINAHL Complete. Only articles published within the last 15 years, those which involved adults, were written in English and those which appeared in academic journals were considered for review. Abstracts of articles returned by searches were checked for relevance before inclusion. Not all articles allowed full text access so they could not be included despite their relevance. An initial search with the terms ‘occupation* therap*’ with ‘specialist seating’ did not return any relevant or accessible articles, neither did ‘seating’ with ‘long term conditions’. A search for ‘seating’ with ‘physical disabilities’ identified one relevant study out of an initial thirteen that were returned. A search with the terms ‘occupation*’ with ‘tilt in space’, and ‘quality of life’ with ‘tilt in space’ returned one article for each set of terms. ‘Function*’ and ‘tilt in space’ produced two relevant articles out of nine. The search was expanded to ‘seating’ and ‘tilt*’ which returned 32 articles – two of which were replicated from earlier searches and five of which were novel and relevant. ‘Quality of life’, ‘function*’ and ‘seating’ returned eleven articles, only one of which was novel, fully accessible and relevant.

Tilt-in-Space and Pressure

The literature review returned two research articles regarding the effect of tilt-in-space on pressure, and one literature review. Sprigle, Maurer and Sorenblum (2010) quantitatively measured changes in pressure distribution over the seat and backrest at various tilted positions for ten wheelchair users with spinal cord injury. Measurements from sensor mats revealed that loading reduced with increasing tilt angles, shifting

weight from the seat to the backrest therefore providing pressure relief, but the authors were unable to conclude how much redistribution was needed to prevent pressure sore. The study was limited due to its very small sample size and the fact that it could not quantify the impact of friction and shear forces which would have given a better picture of the influences on pressure sore development. Sonenblum and Sprigle (2011a) also investigated the pressure relieving qualities of tilting in terms of tissue loading for eleven wheelchair users with spinal cord injuries. The quantitative study identified with the use of specialist sensors the optimal angle of tilt for the best reduction in pressure over the Ischial Tuberosities, therefore reducing the likelihood of pressure ulcer formation. Even small tilts were found to still have some benefit but there was a varied biomechanical response to the tilt, which was theorised to be because of the use of different pressure cushions between participants and a very small sample size. Also the effects of shear and tissue compression were again not taken into account, which are known to be contributing factors to pressure ulcer formation. Michael, Porter and Pountney (2007) conducted a systematic review of experimental, quasi-experimental, controlled observational, observational and expert opinion literature investigating the effects of tilt-in-space with non-ambulant young people and adults with neurological and neuromuscular conditions (typically spinal cord injury and Multiple Sclerosis). They reviewed studies that investigated the angle of tilt, seat configuration, posture and types of cushion and concluded that the tilt-in-space mechanism in wheelchairs caused a significant reduction in pressure loading over the Ischial Tuberosities across a range of conditions. However they also established that there were insufficient articles investigating the effects of tilt-in-space which meant they had to utilise wide search criteria, the majority of studies were quantitative and had low sample sizes, and no studies looked at the long term effects of tilt-in-space. They also could not identify studies investigating the effect of tilt-in-space on fatigue and other physical or social

aspects in the longer term. They therefore also deduced that there was a lack of evidence to guide practice for seating in the existing body of research on changes in health, participation and functional abilities as a result of tilt-in-space seating systems, particularly for those with progressive neurological conditions.

Tilt-in-Space and Other Benefits

The literature review returned seven research articles and one literature review which went beyond pressure redistribution and reported additional benefits of tilt-in-space, developing the argument for the use of tilt-in-space seating for those with mobility restrictions, mirroring the information laid out in the background. Two of the studies found in the literature search did this in a quantitative way. Ding et al. (2008) quantitatively investigated the use of tilt-in-space, among other seating functions, for twelve wheelchair users with a variety of conditions including Multiple Sclerosis and spinal cord injury. Recordings made with a portable device over a two week period during everyday activities, followed by a questionnaire (allowing participants to rate the reasons why the functions were used), showed that participants frequently utilised the tilt-in-space function throughout the day, concluded to be for comfort and postural factors due to fatigue caused by an upright sitting position. The emphasis of this study was on the percentage of time spent utilising the different seating functions and what angles were used, whereas a qualitative focus would have given first-hand experiences of why those functions were used. The study was limited by a fairly small sample size and difficulties with the recording device made the results unreliable. Sonenblum and Sprigle (2011b) also quantitatively examined the use of tilt-in-space, but with a much larger sample size of 45, in wheelchair users with a variety of diagnoses over two

weeks. They found that participants found the main benefits of tilt-in-space to be improving comfort, relieving pain or pressure relief, followed by enabling function, for rest or relaxation, and postural support. Again, a qualitative approach would have broadened the understanding of how tilt-in-space impacted the participants. Similar to the Michael, Porter and Pountney (2007) literature review reported above, a comprehensive literature review by Casey and Gittins (2013) concluded that the evidence base in this area is dominated by research into the design and optimum tilt for seating systems. However the authors also furthered the argument for the benefits of tilt-in-space wheelchairs for adults with physical disabilities by deducing that the function was most commonly utilised for maximising comfort, as well as postural support and managing fatigue. They also identified that there is a need for evidence of the impact of tilt-in-space on health and well-being, functional abilities and quality of life. They also noted that the majority of articles utilised quantitative measurements in randomized controlled trials, which may not have been the most appropriate research method when understanding the topic area, and that qualitative studies or mixed methodologies would have been a more suitable approach in understanding the experience of the seating users.

Three studies from the literature review conducted by the current researcher did look at the experiences of tilt-in-space users in a qualitative way. Lacoste (2003) aimed to improve understanding of how and why people with Multiple Sclerosis, neuromuscular conditions, spinal cord injury and other conditions utilised powered tilt-in-space wheelchairs beyond pressure redistribution benefits, in a subjective way. Focus groups, questionnaires and interviews with 40 Canadian participants, who had used their chairs for at least a year, revealed a high rate of satisfaction of tilt-in-space which was used every day. The most beneficial aspects for the participants were

reported to be improved comfort, better rest and relaxation, pain relief, and for some enabling the completion of activities. These aspects were found to be more important than physiological changes in breathing and bowel function, or the prevention of pressure ulcers for these individuals. The relatively large sample size, varying nature of the participants' conditions, the minimum length of time of seating prescription and qualitative nature of the study all make the results trustworthy, permitting them to be utilised to help aid decision making for clinicians when prescribing seating. However the study focused purely on wheelchair users, which does not allow conclusions to be made regarding the benefits for those who are not wheelchair dependent. In the first study looking at the self-reported experiences of tilt-in-space wheelchair users in the United Kingdom, Dewey, Rice-Oxley and Dean (2004), focused on seven tilt-in-space wheelchair users living with severe disabilities as a result of Multiple Sclerosis, compared to the experiences of sixteen people who utilised conventional wheelchairs with similar levels of disability in a small-scale descriptive study. Qualitative interviews and questionnaires revealed that increased comfort from previous seating was a significant theme, more so than in conventional seating. Also important for participants across both groups was the ability to rest in the chair to relieve fatigue, enabling people to stay out of bed for many hours of the day. However the researchers reported a difficulty in recruitment due to the lack of provision of tilt-in-space wheelchairs resulting in a small sample size, and again the study only investigated those who were severely disabled making it difficult to understand what the benefits would be for those without mobility restrictions as severe. Shankar, Mortenson and Wallace (2015) added to the understanding of the experiences of tilt-in-space wheelchair users in a small-scale exploratory study utilising unstructured observations and repeated qualitative semi-structured interviews with six older adults in residential care. Their results suggested that tilt-in-space promoted control for their users, facilitated

engagement in occupation as well as ensuring comfort and aiding mobilisation. When the tilt function was powered rather than manual, the participants generally experienced a heightened sense of independence, engaged better in occupations, were more able to position themselves and therefore had increased comfort. The study raised interesting comparisons between powered and manual tilt-in-space chairs and highlighted the benefits of tilt-in-space, however it would have been interesting to discuss how tilt-in-space had improved aspects in comparison to their previous seating. Strengths of the study were the use of repeated interviews, and that the participants did not necessarily have neurological conditions, highlighting that tilt-in-space can be beneficial for people with differing causes of restricted mobility. However, the study did not focus purely on the first-hand experiences of the residents. Staff interviews were conducted as part of the research to look at their practice regarding tilt-in-space, and input from family and friends of the participants was relied upon as some participants were unable to communicate. This meant it was difficult to understand the true experiences of those using the seating. As with all the other studies mentioned, it is difficult to say whether tilt-in-space is beneficial for those whose mobility is not poor enough to be wheelchair dependent.

One study revealed a benefit of tilt-in-space that was not highlighted in any of the other studies. Fujita et al. (2010) recognised that for those with restricted mobility due to age or disability, their heightened need of sitting for long periods of time can increase the risk of lower limb oedema (swelling caused by fluid retention). Treatment for oedema is generally to elevate the legs, but this can cause people to slip forward making it more difficult for those with limited mobility to maintain a good posture. In an experimental study with twelve adult healthy males, near-infrared spectroscopy and measurements of

seat pressure revealed that tilting had a significant effect on lower limb circulation which suggested tilting could prevent oedema. However this study only had a small sample of healthy, non-wheelchair users who were not at risk of developing oedema. It would be more conclusive to measure the effects for those who experienced oedema to see if there was a reduction.

One study, which was not necessarily related to tilt-in-space but the current researcher deemed to be appropriate for inclusion, investigated the potential impact of wheelchairs which were individually designed rather than generic. In a pilot study with a semi-crossover design, Trefler et al. (2004) quantitatively measured mobility, posture and reach as well as health status and satisfaction with questionnaires for 24 over 60s living in long-term care facilities, measured longitudinally from original seating through to three months after prescription of individual seating. Overall positive impacts were seen with improvements in all areas which were sustained and continued to improve over time, backed up by clinical observation. Participants were more satisfied with their bespoke system compared with their old seating, with comfort being the main indicator as well as improved postural stability, highlighting the importance of bespoke seating systems. However experiences were not explored qualitatively which would have contributed to the understanding of the benefits for the participants, and there was a large attrition rate, potentially decreasing the power of the results meaning caution had to be taken with reaching conclusions. It would be of interest to investigate individually prescribed armchairs to see if similar benefits could be found compared to wheelchairs.

Principle Research Aim

As shown, the majority of articles found in the literature search concentrated on tilt-in-space in wheelchairs, but the researcher argues that the principles of tilting and its impact on postural support and pressure relief could be applied to arm-chair type seating. Tilt-in-space armchairs have been developed by specialist seating companies which are custom-made to the measurements of each individual, however the benefits of this type of seating has yet to be researched. The current study aimed to extend the investigations from wheelchair users with severe mobility problems to those with neurological conditions or physical disabilities who experience restricted mobility but not necessarily wheelchair dependent. The study was concerned with whether similar benefits would be found to those discovered for tilt-in-space wheelchair users in terms of quality of life and functioning. The literature presented has demonstrated the importance of investigating the first hand experiences of patients in a qualitative way in order to truly understand the experiences of people utilising this type of seating.

Therefore, the primary research aim for the current study was to explore the impact of bespoke tilt-in-space armchairs on the quality of life and functional abilities for individuals with reduced mobility due to a long term condition or physical disability, whose primary reason for requiring specialist seating was for the management of their condition and/or to meet their postural needs. This was done with a qualitative focus, which will be presented and justified in the next chapter along with all other aspects of the study design.

METHODOLOGY

STUDY DESIGN

The current study lent itself to the interpretivist paradigm based on the aims of the research stated above. This paradigm implies that there is no ultimate reality, but that the world is purely a subjective experience for each individual (Barbour 2014). It is argued that people are too complex to be researched in terms of cause and effect, so the utilisation of systematic methods of measurement are not deemed suitable for research aimed at exploring individuals' experiences as they are not able to consider subjectivity (Bowling 2009, Finlay 2006). Therefore a qualitative approach was taken. Qualitative research enables an investigator to look at a chosen subject through individuals' personal narrative in order to highlight their lived experiences (Barbour 2014), which suggested that the aims of the current research fell naturally in line with this design approach. The focus of the study on the experiences of people living with long term conditions or physical disabilities is important to take into consideration. It has been argued that illness cannot be separated from a person's life and therefore its consequences will be experienced in a different way by different people, adding weight to the argument that a qualitative approach was the most appropriate for the current study to allow for the exploration of these differences (Radley 1999).

The study was exploratory in design as the literature above has concentrated on tilt-in-space wheelchairs, with no studies looking at armchair-type seating for those with limited mobility. Exploratory studies aim to investigate topics in order to then formulate a more precise concept, enabling further extensive studies to be designed and

conducted (Neuman 2014). Their descriptive nature allows researchers to discuss how the research can inform policy or practice (Barbour 2014). The current study could therefore allow the development of larger studies which could help develop understanding in this area and therefore have an influence on occupational therapy practice.

This form of research does however have its disadvantages; it is argued that definitive answers cannot be gained, there are few guidelines which make them difficult to conduct, and the direction of the study can change frequently, which means that rigorousness of the research is essential (Neuman 2014).

Research Method

Semi-structured interviews were selected for data collection because they are known to be appropriate for exploratory studies, especially those which aim to study the impact of illness subjectively (Mathieson 1999). Interviews in qualitative research allow a researcher to gain an in-depth look into peoples' experiences, allowing participants to emphasize their most important aspects of the subject in question (Barbour 2014). In addition, interviews are an important tool to allow participants to share and authenticate their differing experiences of illness in a personal context (Mathieson 1999). In particular, semi-structured interviews enable the interviewer to guide the participant through the topic using open-ended questions to facilitate a free-flowing conversation, with the opportunity to clarify questions and probe specific areas in relation to their experiences (Bowling 2009, Clark-Carter 2010). This style of interview allows for flexible questions aimed at gathering rich information from a small sample of people, in

which a planned schedule is followed to allow the researcher to raise questions about certain topic areas highlighted in prior literature, whilst giving the participant space to raise new ideas (Mathieson 1999). A one-time interview in the current study was appropriate as the subject area could be explored in one meeting and would not benefit from repeated interviews (Mathieson 1999).

In this type of research it is very important to achieve authenticity. This involves careful and transparent data analysis and interpretation, being up-front about potential areas of bias and keeping a reflective diary, which can all convince the reader that the research is credible (Ballinger 2006, Bowling 2009). It is important to make clear the value position of the researcher (Barbour 2014). As an occupational therapy student, the researcher in the current study is passionate about improving the lives of people and highlighting areas where a positive difference can be made. It is also essential for researchers to make explicit their natural assumptions that they bring into the research, as it can be argued it is not possible to enter research as an empty vessel (Barbour 2014). For the current study, the researcher had previous practical experience of tilt-in-space seating and the positive impact it can have. There was therefore a potential source of bias as the researcher expected the chairs to make a positive difference, so care was taken to limit the influence of this through peer checking and careful consideration of the interview schedule, development of which will be explained next.

Development of Interview Schedule

An interview schedule was developed to best capture the participants' subjective experiences (see Appendix 6). It aimed to maximise the use of open questions to enable the participants to raise their most important issues, whilst still being guided by the interviewer through the topics of interest (Barbour 2014). As per guidance, the interview schedule was designed to start with gentler questions, in this case regarding superficial aspects of the chair (Barbour 2014). Questions were structured to enable the participant to consider different aspects of their health, guiding them into a discussion about perceived changes in these areas as a result of the new seating in terms of their quality of life and functional abilities. The main areas of concern were based on benefits already discovered in the previous research from the literature search reported above. Probing questions were considered in advance to ensure enough in-depth information was gathered. To close, participants were encouraged to raise novel aspects which the prepared questions had not highlighted, and it was an opportunity to underscore the issues of most importance to each participant, as recommended by Mathieson (2014).

PARTICIPANTS

Participants were selected from the case-load of community-based occupational therapists in the north of England, who acted as gatekeepers for the researcher. The interviews were conducted in the participants' homes, in recognition that people with long term conditions and physical disabilities can struggle to access alternative venues. Lone worker guidelines were followed as per a risk assessment, and potential

participants and/or family members/carers who were deemed to pose a risk to lone working were identified by the gatekeepers and were not invited to take part in the study.

Inclusion Criteria

Participants were invited to take part in the study if they had received, whether privately purchased or funded, a bespoke tilt-in-space armchair at least three months prior to the start of the study. This time frame was selected as an appropriate duration for the participants to have become familiar with the chair. Participants had a diagnosed long term condition or physical disability, whose primary reason for specialist seating prescription was for the management of their condition and/or to meet their postural needs. Participants were only included if they had been deemed to have capacity to consent to the interviews by the gatekeepers.

Exclusion Criteria

Participants were excluded if they lacked capacity to consent to the study. They were also excluded if they were unable to communicate verbally and if English was not their first language, due to time and funding limitations to organise alternative communication aids or translators.

Sample size

The researcher aimed to recruit participants until data saturation was reached to ensure meaningful conclusions could be drawn from the data. This was aimed to be up to a maximum of ten participants. A small number of participants was appropriate for the research design due to its exploratory nature, and qualitative interviews usually recruit few participants due to the production of complex data which is time consuming to analyse (Bowling 2009). It is also recognised that in qualitative research, studies do not aim to be representative of a wider population, but rather reflect diversity and allow for comparison across participants (Barbour 2014). The researcher wished to understand the lived experiences of the participants rather than generalise to other people, lending weight to the decision behind the maximum sample size. Prior to the commencement of the study, the gatekeepers confirmed that recruitment could reach this number based on the individuals on their caseloads who met the inclusion and exclusion criteria

Method of Recruitment

In order to maximise the potential pool of participants who could be recruited, a Professional Development Group of community-based occupational therapists for the same NHS Trust was approached and invited to act as gatekeepers. Three therapists agreed to be involved in the research (see Appendix 1 for confirmation), who selected participants from their case-loads utilising a purposive sampling method due to the necessity for individuals to meet the inclusion and exclusion criteria described above. The gatekeepers were not involved in any other part of the research. Utilising gatekeepers does come with a risk however if they do not fully follow the inclusion or

exclusion criteria as the researcher has no control over which participants are included (Barbour 2014). Another problem associated with this method of recruitment for the current study is the possibility that the participants did not disclose their true experiences, whether positive or negative, due to the gatekeepers being directly involved in the process of the seating prescription, which may have biased the results and effected the validity of the study.

PROCEDURE

Once ethical approval had been gained from the Sheffield Hallam University Dissertation Management Group (Appendix 7), the NHS Research Ethical Committee (Appendix 10) and the Research and Development Office for the NHS Trust involved (Appendix 11), the researcher informed the gatekeepers that recruitment could begin, confirming the specific inclusion and exclusion criteria, the exact process of recruitment and the lone working guidelines that were to be followed. The gatekeepers contacted potential participants by an introductory letter (Appendix 2) introducing the research and asking them to confirm with the gatekeeper whether they would be happy to be contacted by the researcher in an 'opt-in' approach. Those who made this confirmation had their names and addresses passed on to the researcher and were sent a formal invitation letter (Appendix 3) and a participant information sheet (Appendix 4) outlining the aims of the study in more detail. This ensured that the researcher only found out the contact details of those who had provisionally agreed to take part in the study, keeping the identity of those who met the criteria but did not want to be contacted by the researcher anonymous. The gatekeepers only contacted patients on their own caseload so they did not view details of patients they did not have permission

to access. Participants were asked to complete and return the reply slip at the bottom of the invitation letter in an enclosed pre-paid envelope to confirm that they agreed to continue in the study after reading more details. Once the reply slip was received, the researcher contacted each participant by their stated preferred contact method to arrange an interview date and time, and answer any further questions they may have had about the process. The researcher contacted each participant on the day of the interview to ensure they were well enough to continue as planned due to the fluctuating nature of their conditions (participants were notified of this when the interview dates were arranged). It was planned that if the participant was unwell on the day, the interview would be re-arranged to a more convenient time. If their deterioration was likely to continue for longer than six weeks it was planned that the participant would be discounted from the study due to time constraints.

Prior to the commencement of the interviews, the research aims were explained again and participants had an opportunity to ask any further questions. Certain information regarding the procedure was re-iterated from the information sheets - asking to stop for short breaks during the interview if required (for fatigue management purposes – see below for more detail), choosing to not answer questions that made them feel uncomfortable, and choosing to end the interview at any time without needing to give a reason. Each participant was asked to sign two copies of the consent form prior to commencement of the interview (Appendix 5), one to be kept by the participant. Each participant was asked to complete the interview independently from family or carers to minimise the chance of bias. It was planned that if the participant did not feel comfortable with this, a family member/carers could be present in the knowledge that they could not contribute to the interview due to the added dimension it would bring to the study. All interviews were audio recorded with the permission of the participant for

data analysis purposes, as stated on the participant information sheet. The researcher then proceeded with the interview following the interview schedule (Appendix 6). Each participant was only required to complete one interview with the researcher which lasted under 30 minutes. Contact lasted approximately two weeks between the researcher sending out the formal invitation letter and the interview itself. Further contact with the participant was not required unless they requested a summary of the results. The researcher kept a reflective diary during the data collection process in order to note subjective interpretations to decrease the chance of bias impacting the results, and increase the rigour of the study (Bowling 2009).

ETHICAL CONSIDERATIONS

Due to this study involving patients who were part of an NHS service, the researcher applied to the National Research Ethics Service to seek ethical approval. A full ethical review was required due to the interviews having the potential to cause distress to the participants. The completed application form was submitted in June 2015, and a meeting was booked with a Research Ethics Committee based in the north of the UK which was attended by the researcher and their supervisor in July 2015. The committee required further clarification on a number of points before they could approve the study (see Appendix 8 for more detail). These points were actioned, a re-submission was made (see Appendix 9) and the committee gave final ethical approval in August 2015 (Appendix 10).

The main ethical issues involved ensuring there was no ‘cold-calling’ of participants, clarifying how to manage fatigue and minimising the risk of distress for

participants. The procedure laid out above was conducted in a way that ensured an 'opt-in' approach. In recognition of the fact that fatigue is a common symptom for people with long term conditions, it was made explicit in the participant information sheet and in person that short breaks could be taken during the process when needed. If the participant was too fatigued to continue even after a break, it was planned that the interview would be rescheduled for another convenient day, or that they could withdraw themselves from the process completely. It was also explained in the information sheet that whilst the questions in the interview schedule were not designed to cause distress, if the participant became upset whilst discussing their condition the researcher planned to ask them if they wished to take a small break and continue with the interview, or exercise their right to end the interview and withdraw from the process. The gatekeeper involved in the individual's health service would have been contacted with their consent to arrange access to further support services should they require it. These could be condition specific, for example Parkinsons UK/The MS Society, or general, for example McMillan support services. Participants were also informed in the information sheet that should they disclose a safeguarding issue in the process of the interview, the researcher was obligated to inform the local safeguarding team attached to the NHS Trust in question. It was made explicit throughout the process that participants were under no obligation to take part in the study and that they could choose to not continue with the study at any time without giving a reason.

Consent and Anonymity

All participants were provided with a participant information sheet which gave full details of the study so that informed consent could be gained. The interviews were

recorded with a digital audio recorder, and only listened to by the researcher for transcription purposes. Audio files and transcripts were kept on a password-protected computer which was only accessible to the researcher. Portable storage media was also password-protected. Participants were informed of their anonymity throughout the research process, with each having a pseudonym, and the written results only refer to the participants by their pseudonyms. No individual demographics or conditions were linked directly to any of the pseudonyms to ensure that the gatekeepers involved in recruitment were not able to identify their specific answers. The project file containing all hard copies of the documents was kept in a safe place and only accessible to the researcher. All data will be destroyed after 7 years of the completion of the finalised report as per NHS guidance.

DATA ANALYSIS

Interpretative phenomenological analysis (IPA) is concerned with investigating an individual's personal interpretations of the topic in question rather than taking an objective stance, with the researcher utilising interpretative activity to come to an understanding about those interpretations (Smith, Jarman & Osborn 1999). It has been identified as a suitable data analysis method for therapy qualitative research, especially studies aimed at discovering individuals' experiences of illness in an in-depth way, and is typically utilised with semi-structured interview data (Dean, Smith and Payne 2006, Smith, Flowers & Larkin 2009). It was therefore deemed to be an appropriate method of data analysis for the current study. IPA has been found to be a rigorous and valid method of analysis, although it could be argued that the required small sample sizes due to the time-consuming nature of data analysis are a limitation (Pringle et al 2011).

IPA was conducted following a structured set of steps, taken in this case from Biggerstaff & Thomas (2008), Smith, Jarman & Osborn (1999) and Smith, Flowers & Larkin (2009). The recordings of the interviews were first transcribed precisely and then thoroughly read and re-read to allow an immersion in and active engagement with the account, noting anything that seemed significant or interesting, ensuring the participant was kept at the centre of analysis. Using the initial notes, potential themes and concepts at a more abstract level which captured the essence of the data were then identified with key words, including those which were unexpected and contrasting. Connections were then sought between the themes which were clustered together, and a table of themes was produced. This was repeated for all interviews, checking new emerging themes against previous transcripts and seeking patterns across them, ending with a final list of themes. As guided, the researcher ensured that they only engaged with the data without making assumptions or judgements based on previous experience, recording their own emotions and interpretations in a reflective diary.

In the next chapter, the main themes discovered from analysing the data will be presented utilising direct quotations to emphasise the experience of the participants.

RESULTS

In total, the first gatekeeper involved in the study identified six potential participants who were sent out the introductory letter as per the procedure detailed above. Of these, six, four responded positively and agreed to complete the study. Once the four participants had been recruited and the researcher decided that data saturation had not been reached, the researcher contacted the other two gatekeepers who had agreed to be involved in the study to identify potential participants. The gatekeepers did not respond to the researcher's email contact therefore the data collection process stopped with the original four participants. Table 1 shows the demographics of the participants, with their pseudonym names removed to ensure anonymity.

Participant	Age	Diagnosis/Previous Medical History
1	72	Fractured neck of femur <i>Previous history of arthritis and breast cancer</i>
2	58	Multiple Sclerosis
3	57	Multiple System Atrophy
4	59	Dislocated shoulder <i>Previous history of polio</i>

Table 1 – demographic details of participants

IPA revealed two main themes with associated subthemes. The first theme was 'quality of life' which was broken down into two subthemes of comfort and pain relief, and fatigue management and aiding rest. The second theme was 'functional abilities' which was broken down into subthemes of activities and independence. The results will be presented below, with direct quotations from the participants to justify the choice of the themes, followed by other interesting points which were discovered during the process.

QUALITY OF LIFE

Comfort and Pain Relief

All four participants spoke about either an improvement or maintenance of their level of comfort compared to their previous seating. For two, the chair provided a more comfortable place to sit. This was best summed up by the comments by ‘Sue’ who stated that *“just everyday sitting here in a chair, it’s made my life more comfortable”*, which was her biggest perceived benefit of the chair. She described being able to independently change her position to one which was more comfortable at the touch of a button, changing the tilt to shift her weight and alleviate pressure if she was feeling stiff to ensure she did not stay in one position for too long. This enabled her to sit comfortably for long periods of time, in a chair which was not her wheelchair, which she stated was *“marvellous”*. This was in contrast to her previous seating in which she was unable to change position independently which in turn had a negative impact on her mobility, so being able to now change position *“must have done marvels for me really”*. An improved level of comfort was also the most important benefit for ‘Sarah’ who struggled to find comfort in other seating due to her medical history, but the new seat was *“the only chair that I sit on comfortably... I think it’s just made me a lot more comfortable”* which she stated had improved her quality of life. Prior to the tilt-in-space chair she was using her bed to sit during the day as she was unable to stand from regular armchairs, but *“the comfort of the chair is far superior to being on the bed all day”*. She described the relief from discomfort having an unexpected big impact on her life, and brought the issue to life by stating *“if other people tried it you’d realise what it’s like not to be able to sit comfortably”*. For ‘Sally’ and ‘Steve’, the comfort of the

new chair was no different from their previous seating. However they were both no longer able to utilise their previous seating as it had become unsuitable for their needs and level of mobility. In both cases the new chairs provided them enough comfort to be able to sit for hours at a time which had an impact on their respective conditions. The aspect of comfort was not the most important perceived benefit for those participants.

Pain relief was an important feature for both ‘Sally’ and ‘Sue’. Both participants had a long history of muscular pain in their back and/or legs but found that in the chair this was completely alleviated. For ‘Sue’ she stated that what had become a big problem for her prior to the tilt-in-space chair was *“no longer a problem”*, confirmed by ‘Sally’ who stated *“in fact the only two places I don’t have any pain is when I’m sat in the chair and I’m in bed”*. Neither ‘Steve’ nor ‘Sarah’ experienced pain before prescription of their new chair so pain relief was not perceived to be a benefit of the seating for them.

Fatigue Management and Aiding Rest

‘Sue’ described that fatigue was her biggest problem associated with her condition. However she felt that the chair *“really aids the fatigue a lot”* and has helped her to manage her fatigue levels, so much so that she felt she did not experience the same problems anymore. For this reason she explained that she always made a conscious decision to head for the chair when she felt fatigued as it provided enough relief for her to be able to sleep during the day. Whilst being unsure whether it had a big impact on fatigue levels, both ‘Sarah’ and ‘Steve’ on reflection recognised that they both would choose to use the chair to rest when feeling fatigued rather than going back to bed during the day in the knowledge that they would be comfortable and be able to sleep

properly. For one, being able to rest properly had a direct impact on their energy levels the next day, effecting their mobility and speech, and they were able to sit for hours at a time in the chair, sleeping when necessary, without causing any further fatigue. Whilst acknowledging that it was a good place to rest, neither felt that this was their most important benefit of the tilt-in-space seating. ‘Sally’ frequently felt fatigued however she did not perceive the chair to have made any difference to her fatigue levels, attributed to an underlying condition (anaemia).

To summarise, despite differing diagnoses, all participants reported that the seating enabled them to maintain, or in some cases improve, different aspects of their quality of life either in terms of their comfort and pain relief, or managing their fatigue levels whilst living daily with a long term condition or physical disability. In all cases, the seating was provided at a point when deteriorating mobility meant that alternative seating was no longer appropriate, therefore a solution was needed that ensured they could continue to live with a good quality of life whilst being sat for prolonged periods of time. For some, to be able to sit comfortably and rest during the day had a direct impact on their symptoms, meaning the chair became an effective way to manage their condition.

FUNCTIONAL ABILITIES

Activities

One participant spoke about an improved ability to complete activities. For her the most important feature of the tilt-in-space chair was for her to be able to keep active and engage in her chosen hobbies whilst keeping her legs elevated to manage oedema. Prior to the chair she was unable to complete the activities which were important to her at the same time as sitting with her legs elevated, as her previous seating caused her hip angle to open up, resulting in a laid back position which restricted the activities that she could do: *“I couldn’t even read a book or anything”*. With the tilt-in-space seating however, she was able stay upright in a functional position whilst having her legs elevated, finding it easier to complete the activities of her choice: *“yes I think I can do more sat in that chair than I could before”*. For the other three participants, they spoke about the chair enabling them to maintain their previous activity levels rather than improve. It was important to ‘Sarah’ to keep busy and active which her previous seating (the bed) enabled her to do, but she recognised that this would not be possible in any other type of armchair which would have aided her standing transfer due to her inability to cope with the opened up hip position. She therefore required the tilt-in-space function to be able to sit in a position which enabled her to continue doing the things which were important to her whilst finding comfort out of the bed and having standing assistance. ‘Steve’ also recognised that without the chair, his activity levels may have had to decrease but this was tricky to say for definite as he could complete the activities he wished in his previous seating, but this had become unusable due to his deteriorating muscle strength. He did state that *“the chair has enabled me to continue doing those things now...if it was absent maybe I would struggle to do certain things”*

and that *“if I hadn’t got it I think it would certainly have impacted normal activities”*. He also stated that the chair helped preserve his energy levels enough to be able to complete family activities such as walking in the park. However prescription of the chair did have an unforeseen negative consequence in terms of the family activities and roles he engaged in. He spoke about losing an element of family life which was important to him and his family due to the chair being a single seat, rather than the sofa that he was utilising before - *“I don’t have the physical contact in the same way I might have done in the past...It’s removed me a little bit from what you would consider as normal family life”*. ‘Sue’ did not really notice a difference in her activity levels, rather it enhanced what she could already do by ensuring she used her energy appropriately.

Independence

All participants were able to maintain their independence in standing and transfers in the face of deteriorating mobility, or as a result of injury that affected their ability to stand. For ‘Steve’, maintaining independence and safety were the most important benefits of the seating. His previous seating was making it unsafe for him to stand independently as it had become inappropriate for his needs due to deteriorating mobility and muscle strength, causing him to lose balance and leaving him at risk of falling. Without intervention this may have meant he needed additional support to stand. The tilt-in-space chair however brought him to the best position and height for him to be able to stand independently with minimal effort, allowing him to stand as many times as needed throughout the day without needing support from family members to continue with his daily life. This was clearly significant for him as he stated *“I think it’s important not to have to rely on a family member”*. This meant he could spend time on his own in the house in the knowledge that he would be safe (and allowing his wife to

continue to work which he told the researcher after the interview recording had stopped), easing pressure off the family as they could go out “*without too much hesitation and worry about whether I can cope or not without them*”. ‘Sue’ also spoke about deteriorating mobility and then an unexpected injury which led her to struggle to independently transfer from an armchair into her wheelchair. Her previous seating was negatively impacting her mobility, and she mentioned that this had made it difficult for her to get to the bathroom in time, whereas after receiving the chair (with modifications which will be explained below) she no longer struggled. She also mentioned safety – “*I know I’m safe within it*” which then had an impact on her carers – and the importance of being able to independently shift position as explained in more detail above. Deteriorating mobility compounded by an immediate unexpected problem was also the reason for seating prescription for ‘Sarah’, who had lost her ability to independently stand from a regular armchair as “*it was a laborious movement to get upright again*”, meaning she spent her time sat on her bed. With the chair however, it raised her to the right height to be able to stand, meaning she regained her ability to stand independently – “*it’s a lot less stressful and tiring to be able to stand up*”. ‘Sally’ also had progressively struggled to transfer out of her previous seating to a point where this had become too difficult to complete independently, whereas now she was fully independent in the chair.

In summary, all participants across a variety of diagnoses and medical histories described being able to maintain or improve their activity levels in the chairs, further adding to their ability to sit for prolonged periods of time. This was dependent on their personal circumstances, previous seating arrangements and priorities for seating prescription. The chairs also enabled all participants to maintain a level of

independence despite deteriorating mobility which held different meaning for different participants.

FURTHER POINTS OF INTEREST

Individuality

All four participants received a bespoke chair, but they all highlighted how it was custom-made for them, and for some this meant taking into account their future needs. All four participants had chairs that were made specifically to their measurements in terms of width, depth and height. The importance of having a bespoke chair came to life in ‘Sarah’s’ interview who described a member of her family who bought a standard chair which was not made to her specific measurements – *“it was really bad for her because there was a big gap at the back and she could never get quite comfortable...and it was too wide”* which created more problems for her and had a negative impact on her life as *“it wasn’t doing the right things for her”*. As well as the standard practice of being made to measure, ‘Sarah’ explained how her chair did not tip like other chairs; instead it just raised her to the right height to be able to stand which was specific to her and her requirements. However she also described it could not fully take into account her needs as she requested a table to be added onto the chair to allow her to carry out different activities, but this was not something they could incorporate at the time of prescription. ‘Sue’ recognised that *“this [new chair] is better than that [old armchair] because it, it’s more customised to me and my needs....this is more compact to my shape”* which impacted the comfort and usability of the chair. This was an unexpected positive element for her. She also had modifications made to the chair

which assisted her to shift her weight forward to be able to transfer independently, acknowledging that without it the chair would not have been able to meet her needs. She also had an air cushion which she could adjust according to her preference and level of stability needed. The chair was also able to fit in with her other standing aids. For 'Steve', as well as being customised to his size and preferences in terms of design and integrating with the rest of the furniture in the house, the arms of the chair were adjustable in height allowing for side transfers meaning that *"it's somewhat future proof"*. He expected further deterioration due to his condition, therefore by realistically looking at his future needs he was provided a chair that *"works for me today but hopefully will allow me to stay independent in the future as well"*. Pressure care could also be added in at a later stage should his pressure care needs become more significant. As well as taking into account her stature, pressure care was something that was added in for 'Sally', despite not currently requiring it therefore also taking into account her future needs. She had been provided a head rest, however this had become too uncomfortable for her to use due to a worsening medical condition. This was removable though which meant she could still use the chair without it. However there was an unexpected problem which caused her some discomfort. The pressure care material stuck to the skin on her legs which had become damaged with oedema, so her individual need in this respect was not taken into account.

In summary, by having different conditions and reasons for specialist seating prescription, all participants required something different out of their seating, which meant a full assessment was needed to take into account their differing current and future needs. Due to all participants having unique perceived main benefits of the seating, this further adds weight to the importance of individualised seating.

Funding

Three of the four participants mentioned without prompting about the cost implications of the chairs. For them, the fact that they were able to get the chair funded was incredibly important. ‘Sue’ *“could only have it if there was funding there”* due to its expense, and the decision to purchase it was delayed until a decision was made on the funding, which appeared to be *“pot luck”*. This was also confirmed by ‘Steve’ who recognised that *“we would have struggled to have got the chair without the assistance that [OT] provided because they’re not cheap....we would not have the chair had she not intervened”*. ‘Sarah’ furthered the argument that *“funding is the core issue”* and explained that she felt lucky to have received the chair as the funders kept *“changing goalposts for her [OT] for applications”*. She explained that she thought that this type of seating should have mainstream funding like wheelchairs, reflecting the point that *“people spend a lot more time in the home then they do out and about in a wheelchair don’t they?”*, and that there needed to be a consistent approach. This highlights the importance of funding options for specialist seating.

The implication of these results will be explored and discussed further in the next chapter.

DISCUSSION

The aim of the current research was to qualitatively investigate the impact of specialist tilt-in-space armchair seating on the quality of life and functional abilities of adults living with long term conditions or physical disabilities. This was an area that had previously not been researched, with the majority of literature focusing on tilt-in-space wheelchairs. This chapter will present a discussion of the results reported in the previous chapter, linked with the research considered earlier. Implications for practice and potential areas of further study will then be discussed, along with the strengths and potential limitations of the current research.

QUALITY OF LIFE

Comfort and Pain Relief

The current results revealed that the tilt-in-space seating either provided more comfort for the participants, or enabled them to continue to have enough comfort to remain seated for prolonged periods when other seating could not meet their needs. This finding reflects the results of the literature reported earlier which investigated the impact of tilt-in-space space beyond pressure redistribution benefits. The quantitative studies (Ding et al. 2008, Sonenblum & Sprigle 2011b, supported by Michael, Porter & Pountney 2007 literature review) started to reveal that tilt-in-space could provide comfort for adults with Multiple Sclerosis, spinal cord injury and other physical disabilities. This was supported with the qualitative research of Lacoste (2003),

Dewey, Rice-Oxley & Dean (2004) and Shankar, Mortenson & Wallace (2015) who discovered from the experiences of adults with neurological conditions and other disabilities that improved comfort was a significant benefit of tilt-in-space. These studies suggested that comfort was a benefit across a range of neurological conditions and physical disabilities which the current study has also done, as all participants had different diagnoses and medical histories.

The variability in diagnoses however could be attributed to the disparity between the results in this area. Lacoste (2003) emphasised the importance of comfort in specialist seating by declaring it is one of the most crucial aspects, which was found to be true for two of the participants in the current study. However for the other two this was not the most important benefit, highlighting that every individual who can benefit from tilt-in-space may have a different priority for seating prescription. The difficulties associated with this will be explored later on. Discomfort in seating can lead to impaired function, reduced quality of life and development of inappropriate postures to relieve pain (Crane 2007 in Cook & Polgar 2015). Therefore even if improved comfort is not a main priority for individuals with limited mobility, if discomfort can be avoided through prescription of tilt-in-space these detrimental consequences can be avoided. It is also possible that had the seating been provided at a different time in the journey of their condition, these participants would have found the comfort aspect to be more important. Despite this disparity, for all participants in the current study the tilt-in-space feature was found to enable them to sit in a good postural position, allowing them to sit for many hours of the day in comfort. Dewey, Rice-Oxley and Dean (2004) noted that their participants (individuals living with Multiple Sclerosis) described the importance of being able to find somewhere comfortable to sit during the day without being in bed. The results of the current study have shown that

seating of this kind provides enough comfort to enable people to do this, which can aid with the management of their condition, regardless of whether this was aspect perceived to be the main priority for the individuals. Comfort was also the main benefit for individuals with bespoke wheelchairs rather than generic ones (Trefler et al. 2004), which could also help to explain the results of the current study in which all participants received a chair which was custom-made for their exact measurements. The current research therefore suggests that comfort is an important advantage of bespoke tilt-in-space seating for adults who have restricted mobility but are not necessarily at the stage of being wheelchair dependent, extending the benefits of tilt-in-space from wheelchairs to armchairs.

The results showing that the tilt-in-space seating provided complete relief from a long history of pain for some participants are also in line with the literature highlighted earlier, namely Lacoste 2003 and Sonenblum and Sprigle 2011b. This result is not surprising as it was mentioned in the background the importance of maintaining good postural alignment to relieve back pain (Cook & Polgar 2015). Tilt-in-space could therefore be beneficial for those who regularly experience pain due to its ability to ensure the maintenance of an optimal sitting posture. Even though not explicitly mentioned by the participants, the researcher wonders whether there would be a psychological impact of living daily with discomfort or experiencing pain on a regular basis due to their mobility limitations. Chronic pain has been shown to undermine a person's sense of self related to an ongoing process of managing intrusive experiences that are beyond a person's control (Smith & Osborn 2007). To then be provided with a solution that eradicates pain might then be able to start to improve the individual's sense of self. A sense of relief was allowed to be revealed to the researcher due to the qualitative nature of the study, enabling this experience to come to life from the first-

hand accounts of the individuals themselves in a way quantitative studies would not have permitted. For those who did not experience pain relieving benefits due to not living with pain before the seating provision, it is possible that the tilt-in-space function ensures they maintain an optimal sitting position, avoiding the development of a poor sitting posture which is linked with physiological changes and pain (Hendrie 2009). This could mean that their new seating could prevent the development of such problems. Of course this would not be possible to be determined for the current participants even if the study were to be extended, as it would not be possible to determine how their posture would have changed had they not received the chair.

Fatigue Management and Aiding Rest

Previous quantitative and qualitative studies by Ding et al. (2008) and Dewey, Rice-Oxley and Dean (2004), supported by the literature review of Casey & Gittins (2013), reported on the benefits of tilt-in-space wheelchairs in aiding individuals with neurological conditions and physical disabilities to manage their fatigue levels. This was true for one participant in the current study who, as the results described, no longer felt she experienced fatigue to the same extent which was of significance for her. Lacoste (2003) and Sonenblum and Sprigle (2011a) extended the aspect of fatigue management to explain that tilt-in-space was utilised by wheelchair users to aid rest and relaxation, enabling them to sit in the chair for many hours of the day without going back to bed. This was true for two participants who, as described in the results acknowledged they would utilise the chair to rest in during the day, although it was not their perceived main benefit of the chairs. Dewey, Rice-Oxley & Dean (2004)

explained the importance for their participants of being able to sit in a chair rather than returning to bed during the day, meaning it was essential for them to have a wheelchair that enabled them to rest when they felt fatigued. This was reflected in the current study, emphasising the importance of having seating that enables individuals to do this despite not necessarily requiring a wheelchair. Again, if staying out of bed is an important issue for people with physical disabilities or neurological conditions, the researcher questions whether there is a positive psychological impact of being able to remain out of bed in the knowledge they have the a place to rest should they need it.

The benefit of enabling people to manage their fatigue levels and aiding rest can be understood by revisiting the importance of good posture and seating as laid out earlier. People with neurological conditions become fatigued easily, which can be worsened by the extra demands on the body if seated in an inappropriate posture (Pope et al. 1988 in Dewey, Rice-Oxley & Dean 2004). Gravitational forces, as well as potentially leading to soft tissue damage and postural deformities if a person cannot hold themselves in an appropriate position, also makes sitting more of an effort for people with muscle weakness. Tilt-in-space however promotes an optimal sitting posture with the trunk in midline, and therefore removes the necessity for people with reduced muscle tone and strength to hold themselves against gravity, allowing the body to relax therefore relieving fatigue (Collins 2005). The ability to maintain an optimal seating posture through tilting also increases stability, which is important for energy conservation (Long 2014). Fatigue can severely restrict peoples' ability to engage in everyday activities, as well as having a negative impact psychologically and socially (Finlayson, Preissner & Cho 2012, Payne, Wiffen & Martin 2012). If the tilted position can help people manage their available energy levels through promoting rest, it is possible that people may be able to conserve limited energy resources to allow them to

direct it into the activities of personal value as well as seeing an improvement in physical health, psychological health, and social functioning. The impact on functioning will be discussed in more detail below.

Whether participants found fatigue management or aiding rest to be a significant benefit or not could be due to all four participants having different conditions and medical histories, and therefore having different pathological causes of fatigue, symptom management needs and individual priorities for seating. Also, all of the participants had only had their chairs for a maximum of seven months, which may not be long enough for the participants to recognise a big change in their fatigue levels. Long term neurological conditions are generally progressive in nature however, with fatigue being a common experience which can worsen with time, so it is essential to recognise that it may be more realistic to look at equipment in terms of managing fatigue and providing a place of rest rather than alleviating it completely. These results do seem to suggest that the benefits of tilt-in-space on providing a place of rest outside of bed can be extended from people with severe disabilities to those with limited mobility but not necessarily wheelchair dependent. Greater fatigue is linked with a worse perceived quality of life so by providing a solution enabling people to manage their energy levels there should be an improvement in health-related quality of life (Pittion-Vouyovitch et al. 2006). Occupational therapists regularly support adults who experience fatigue to manage their energy levels (Finlayson, Preissner & Cho 2012), so if tilt-in-space seating can help people in this area it could be valuable equipment to take into consideration for people who are required to sit for long periods of time.

Seating may initially seem outside the remit of occupational therapy. However the profession is concerned with assessing an individual's holistic needs when living with a

variety of conditions. The findings that the quality of life of people living with disabilities can be improved through seating intervention helps to establish the role of occupational therapy in this area (Herzberg 1993).

FUNCTIONAL ABILITIES

Activities

For wheelchair users, Lacoste (2003), Sonenblum and Sprigle (2011a), and Shankar, Mortenson and Wallace (2015) discovered in their studies that tilt-in-space facilitated individuals with neurological conditions and physical disabilities to engage in activities. These results have been extended in the current study to suggest that tilt-in-space can also be beneficial for adults with a variety of diagnoses and medical histories who are not necessarily wheelchair dependent but require to be sat for many hours of the day due to restricted mobility. However this study has revealed that the benefit of tilt-in-space seating may be ensuring that occupational performance does not deteriorate with declining health and mobility, rather than returning function to those who had lost this ability. As highlighted in the background, tilt-in-space ensures the maintenance of an optimal seating position dependent on task demands by allowing people to independently reposition (Collins 2005, Lacoste 2003). This postural alignment keeps them in the best functional position and improves occupational performance (Cook & Polgar 2015). This means that individuals do not have to sacrifice what activities they complete whilst trying to find comfort in a chair, which could lead to frustration for individuals who like to keep busy, which was true for some participants as shown in the

results. If this leads to people feeling like they can stay sat for longer, this can help with aspects of condition management (such as energy conservation as already discussed), ensuring they maintain chosen aspects of their lifestyles as much as possible. Therefore even if tilt-in-space is provided before functional abilities are negatively impacted by bad posture, the maintenance of a good sitting position should ensure that people do not experience a loss of meaningful activity or reduction in the roles they perform. In terms of enabling people to maintain their previous roles, the unforeseen negative aspect of the chair reported in the results is important to note. The seating had shown to influence the normal routines within a family in an undesirable way, which could perhaps change a person's role and the dynamics within a family. This is an important factor to take into account when providing equipment, especially for those with conditions which are progressive in nature and support within the family is essential.

The impact of tilt-in-space seating on functional abilities re-iterates the role of occupational therapy in seating provision due to its concern with enabling people to maximise the ability to perform meaningful occupations and participate in chosen roles and routines (Harrison 2007, Reid, Brault & Croteau 2009). The current results highlight the importance for therapists to predict which people may experience a reduction in functional abilities due to deteriorating mobility or postural factors, and pre-empt it by recommending equipment such as tilt-in-space seating which may act as a preventative measure. Timing and clinical knowledge is therefore essential in this complex decision making process.

Independence

The level of independence that the chairs provided is an important aspect to discuss in terms of the participants' functional abilities. The importance of this factor has not been emphasised in the previous literature, except for the Shankar, Mortenson & Wallace (2015) where independence was linked to a powered tilt-in-space function in wheelchairs rather than a manual function enabling people to adjust the angle of tilt independently. This was not surprising with the knowledge that previous studies focused on wheelchair users with more severe levels of disability. For all participants in the current study, the chairs enabled them to transfer independently at a time when this act had become a struggle due to deteriorating mobility. The researcher questions whether a continuance of inappropriate seating would mean that the participants would have become dependent on others for moving, potentially with the need for carers, whereas the new seating has enabled them to utilise their mobility to its best. The qualitative nature of the interviews allowed the participants to express the importance of this issue to them in a way previous quantitative studies would not have allowed. The results showed that this could have an impact on family life, with additional pressure being lifted from family members and enabling people with deteriorating health to continue functioning in their normal roles and lifestyle as much as possible whilst living with their condition. The notion of safety was also raised as the chair resulted in a reduction in the occurrence of falls which could be important for peoples' sense of independence. Enabling individual's independence can have many positive benefits, including functional improvements as already discussed, increasing social interactions, maintaining general health and creating a positive self-image (Cook & Polgar 2015). By ensuring that people can continue to be independent for as long as possible whilst living with a long term condition or physical disability, particularly in the face of

declining health and mobility, seating of this type can therefore play a part in these areas. Guidelines from the government state that all people with long term conditions should receive support for their complex and changing needs, including equipment that will enable an individual to live as independently as possible (Great Britain, Department of Health 2005), therefore seating of this type should be considered for adults with deteriorating mobility. Occupational therapy is a key profession in enabling people to maintain their independence when living with a variety of conditions, again highlighting the importance of the profession in seating provision.

A surprising result of the study was that postural support and pressure relief did not feature as important aspects for the participants, other than that the chair was suited to their posture, despite previous literature finding this being a benefit (Sprigle, Maurer & Sorenblum 2010, Sonenblum and Sprigle 2011a+b, Michael, Porter & Pountney 2007, Ding et al. 2008, Casey and Gittins 2013). The only physiological benefit that was seen was the reduction of oedema for one participant, reflecting the results of Fujita et al. (2008). The results instead reflected those of Lacoste (2003) who found that the majority of participants perceived the benefits of tilt-in-space to be in terms of providing comfort, aiding rest and relaxation, relieving pain and enabling the completion of activities, rather than the prevention of pressure ulcers and other physiological changes. It is possible however that due to the fact that the chairs were provided in line with deteriorating mobility, the new tilted position enabled the individuals to sit in a more appropriate posture, and thereby putting the body at the least risk of damage by minimising the pressure and shear on the skin (Hendrie 2009, NPUA Panel, EPUA Panel and PPPIA 2014). The timing of seating provision is again

therefore important. If seating can be provided to people who are likely to require to be sat for long periods of times before postural changes and pressure sores become a problem, their occurrence could be prevented. This requires a full understanding of the trajectories of different conditions for therapists to be able to prescribe seating appropriately.

FURTHER POINTS OF INTEREST

Individuality

The finding that the chair was able to match each participant's holistic requirements has highlighted the necessity for a complete assessment to be undertaken of a person's needs in a purely client-centred way. This is particularly important as not everyone with the same diagnosis will experience the same impairments (Cook & Polgar 2015); therefore each chair needs to be suitable for each individual that requires specialist seating. The importance of custom-made chairs in the current study was in line with Trefler et al. (2004) who stressed the positive impact of bespoke wheelchairs for satisfaction and comfort. The importance of comfort has already been discussed above. These results show that in order for tilt-in-space seats to have the best impact in terms of quality of life and functional abilities as highlighted above, the seating must be custom made for them, taking into account their exact measurements and needs. The results have expanded the importance of tilt-in-space from wheelchairs to armchairs for adults with restricted mobility who are not necessarily wheelchair dependent. By fully assessing a person and taking into account all of their health needs and the long term

requirements of each person at the assessment phase, particularly for those with progressive conditions, it can be ensured that the seating remains effective and does not become redundant (Collins 2007, Tierney 2013). This was also highlighted in the current study. The importance of fully taking into account all of a person's needs were also highlighted by the unforeseen problems raised by the participants. The annoyance and frustration that could result from not assessing needs fully could lead to the chair not being used appropriately or for the amount of time required to manage people's conditions effectively. Occupational therapists are trained to holistically assess all aspects of their patients' lives, making them an ideal profession to provide advice on seating, but it does require a thorough knowledge of different conditions and how they are likely to impact them in the future.

Funding

Unfortunately, equipment which is designed specifically to take into account each individual's need in a bespoke way is generally more expensive than generic items (Cook & Polgar 2015). The majority of the participants raised the issue of the cost of the chairs, and that without funding it would have not been possible to purchase it. The expense of assistive technology could contribute to a significant financial burden to families who have already had to purchase expensive disability equipment, making funding important (Dewey, Rice-Oxley & Dean 2004, Cook & Polgar 2015). However it is becoming more difficult to access assistive technology due to public funding cuts and clinical services becoming more limited (Cook & Polgar 2015). Also, not all localities have the same policy for funding equipment of this nature, despite guidelines

that state equipment should be provided which enables independence and improves quality of life for those with long term conditions (Great Britain, Department of Health 2005). There may be potential ways to overcome the funding barrier. Li Pi Shan et al. (2007) trialled a cost savings model for wheelchairs in Canada on a reuse and refurbish basis which may be something to consider for tilt-in-space armchairs in this country.

IMPLICATIONS FOR PRACTICE AND FUTURE STUDY

The current results have shown that bespoke tilt-in-space armchairs can have an impact on differing aspects of quality of life and functional abilities for adults with long term conditions or physical disabilities. All the participants in the current study had different medical histories and conditions, highlighting that this type of seating can be beneficial for a wide range of people, although it has also been revealed that the perceived benefits of the seating are individual to each person and their needs. Occupational therapists play an integral role in holistically enabling people to maintain their chosen lifestyle whilst living with medical conditions, so they are the appropriate professionals to consider equipment such as seating which can allow people to do this. It is therefore essential that therapists are aware of the impact tilt-in-space seating can have, and this research has begun to highlight which service users could benefit from this type of seating. Seating provision can be a complex decision making process, as the high cost has to be weighed against what benefits can be gained for that person on an individual basis, ensuring seating is provided at the right point in the journey of their condition to act as a preventative measure from postural deformities and associated problems. However, this type of equipment is very expensive, and could place an added financial burden onto those living with long term conditions. If further research confirms these initial results, it may be worthwhile to encourage commissioners to look into funding options and to ensure this is consistent across NHS Trusts. If the seating enables people to remain independent for longer, this may have an impact on the type of support from carers in the future, which comes with a price tag. If prescribed at an appropriate time, they may also help prevent the development of pressure sores and further physiological complications which can be expensive for the NHS to treat, so if the chairs are confirmed to be a preventative measure, they may prove to be cost-effective.

The researcher would suggest that further research could take this study as a starting point and delve more in-depth into the impact this type of seating can have on people's lives, with a larger number of participants. The participants in this study received their chairs relatively recently before the start of the study (four to six months approximately) so it would be interesting to include a longitudinal aspect to the study to assess how the chairs impacted health and wellbeing over a longer period of time. It may also be interesting to look at different client groups separately to better understand the main benefits for people with varying needs, however this would not be possible until this type of seating becomes more regularly prescribed.

STRENGTHS AND LIMITATIONS

The current study enabled an initial exploration into the experiences of adults with long term conditions and physical disabilities who have been provided tilt-in-space armchairs. Due to the lack of available literature for armchair-type seating, the study used literature on tilt-in-space wheelchairs as a basis for the investigation. By doing this, the interview schedule was designed to explore expected outcomes based on the benefits seen in the literature, whilst allowing new information to come to the surface. It was important to utilise a qualitative methodology to investigate the subjective experience of those using this type of seating system, as it helps readers to get a sense of the type of problems people encounter in their day-to-day life. Transparency was ensured by the researcher stating from the beginning of the process their potential bias towards the results, and by keeping a reflective diary throughout the process. Peer

checking was also utilised for authenticity and to ensure that the highlighted themes were appropriate and accurately represented the data.

However the study did have some limitations which need discussing. The sample size for the study was lower than expected and the data saturation point was not met. Each participant raised a different perceived main benefit of the seating, and more participants may have provided more clarity. The researcher did plan to ensure that a higher number of participants could be recruited, however these avenues could not be pursued due to two of the three gatekeepers who had agreed to be involved in the study not replying to contact from the researcher. The researcher had planned to approach the professional development group a second time for further gatekeepers however the time pressures of the study did not allow for this. This has shown the potential limitations of utilising gatekeepers for participant recruitment. Whilst gatekeepers can be beneficial in recruitment to ensure participants are accessible, they can also be a barrier to the study, as experienced in this research. However due to the researcher not currently being in practice and not having access to participants who met the inclusion criteria, this study would have not been able to have been completed with this design without the use of gatekeepers. It has been noted that small sample sizes in this type of study are common due to difficulty with recruitment because of a lack of provision of tilt-in-space seating (Dewey, Rice-Oxley & Dean 2004).

In terms of time pressures, the ethical process that was required to be followed hindered the process of the study. Whilst it was essential to gain ethical approval in order to protect the participants involved, the process of submission and the demands of

the ethical panel described earlier caused delays in gaining approval which had a knock-on effect to the rest of the study.

There was also a lot of variability within the participants in terms of their diagnosed conditions and medical histories which made it more difficult to reach a final conclusion regarding the main primary benefits due to differing priorities for seating and differing prognoses for each participant. Whilst this variability has shown that tilt-in-space can be beneficial for people living with a variety of conditions, it does make it more difficult for there to be a consensus. However, the research highlighted in the literature review suggested that tilt-in-space wheelchairs had similar benefits whether looking at the same or different conditions, whether neurological or physical in nature. This means that this study can take tentative steps to suggest these results would be the same if the research focused on individuals with the same condition, but it would be interesting to look at whether there would be any differences in seating priorities for people with different diagnoses. Again, this would be difficult to rectify due to the lack of tilt-in-space seating.

Also, the length of time the participants had been using their chairs for was quite small (four to seven months) which might have resulted in them not fully understanding the benefits of the chair yet. Lacoste (2003) recruited participants who had been utilising their wheelchairs for over a year when investigating their experiences, which may have given them more time to realise the benefits of the seating. The researcher was unable to raise the minimum length of time from three months however as none of the patients involved in the service would have met the criteria and the study would not have recruited any participants. Taking all of this into account however, the research has made some strides into beginning to understand the benefits of tilt-in-space for adults with long term conditions and physical disabilities.

CONCLUSION

The aim of this study was to investigate the impact of bespoke tilt-in-space seating on the quality of life and functional abilities for adults living with long term conditions or physical disabilities. Previous studies have typically been focused on tilt-in-space wheelchairs for those with severe disabilities, and have either typically utilised quantitative methodologies or did not look at the first-hand experiences of the participants. This study has expanded the benefits of tilt-in-space from adults with severe levels of disability in previous research, to those with other disabilities and causes of limited and/or deteriorating mobility who also sit for prolonged periods of time, and for those who are not wheelchair dependent. It has been concluded that there are some benefits of this function in armchairs in terms of comfort and relieving pain, managing fatigue and aiding rest, maintaining activity levels and enabling independence. All participants spoke about a different aspect which was their perceived main benefit, highlighting that seating priorities are individual in nature based on their lifestyle and symptoms of their condition. For this reason, the bespoke nature of the chair is essential. In order to understand this area in more depth, further research would need to recruit more participants, potentially separating them into condition-specific groups however due to a lack of seating provision this would be difficult to achieve. Occupational therapists need to be aware of the potential impact of specialist tilt-in-space seating for adults with long term conditions and physical disabilities to ensure they are provided with equipment that will help them maintain their quality of life and independence in the face of deteriorating health and mobility. However funding options may need to be discussed to ensure this client group does not have a further financial burden.

REFERENCES

- BALLINGER, Claire (2006). Demonstrating Rigour and Quality. [online]. In: FINLAY, Linda. & BALLINGER, Claire (eds.). *Qualitative research for allied health professionals: challenging choices*. Chichester, John Wiley & Sons Limited, 235-246
- BARBOUR, Rosaline (2014). *Introducing Qualitative Research: A Student's Guide*. 2nd ed. London, Sage Publications
- BIGGERSTAFF, Deborah and THOMPSON, Andrew (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. [online]. *Qualitative Research in Psychology*, 5, 214-224
- BOWLING, Ann (2009). *Research Methods in Health Investigating Health and Health Services*. [online]. 3rd ed., Berkshire, McGraw Hill Education
- CAREFLEX (2016). *The Importance of Good Sitting Posture*. [online]. Last updated 2016. Last accessed 20 January 2016 at: <http://www.careflex.co.uk/what-is-specialist-seating/your-careflex-guide-to-specialist-seating/sitting-posture>
- CASEY, Jackie and GITTINS, Lyndsay (2013). The use of tilt-in-space in seating systems for people with physical disabilities. [online]. *Physical Therapy Reviews*, 18 (4), 285-299
- CLARK-CARTER, David (2010). *Quantitative Psychological Research: The Complete Student's Companion*. [online]. 3rd ed. Sussex, Psychology Press
- COLLINS, Fiona (2005). Product Focus: The Ibis XP tilt-in-space powered wheelchair: A review. [online]. *International Journal of Therapy and Rehabilitation*, 12 (11), 510-514
- COLLINS, Fiona (2007). Product Focus: The HydroTilt Armchair: Meeting complex seating requirements. [online]. *International Journal of Therapy and Rehabilitation*, 14 (2), 83-88
- COOK, Albert M. and POLGAR, Janice M. (2015). *Assistive Technologies Principles and Practice*. 4th ed. St. Louis, Mosby Elsevier

CRANE, Barbara A. et al. (2007). Responsiveness of the TAWC tool for assessing wheelchair discomfort. [online]. *Disability and Rehabilitation: Assistive Technology*, 2 (2), 97-103

DEAN, Sarah, SMITH, Jonathan and PAYNE, Sheila (2006). Low Back Pain: Exploring the Meaning of Exercise Management through Interpretive Phenomenological Analysis (IPA). [online]. In: FINLAY, Linda and BALLINGER, Claire (eds.). *Qualitative research for allied health professionals: challenging choices*. Chichester, John Wiley & Sons Limited, 139-155

DEWEY, Ann, RICE-OXLEY, Margaret and DEAN, Taraneh (2004). A Qualitative Study Comparing the Experiences of Tilt-in-Space Wheelchair Use and Conventional Wheelchair Use by Clients Severely Disabled with Multiple Sclerosis. [online]. *British Journal of Occupational Therapy*, 67 (2), 65-74

DING, Dan et al. (2008). Usage of tilt-in-space, recline, and elevation seating functions in natural environments of wheelchair users. [online]. *Journal of Rehabilitation Research and Development*, 45 (7), 973-984

FINLAY, Linda (2006). Going Exploring: the Nature of Qualitative Research. [online]. In: FINLAY, Linda and BALLINGER, Claire (eds.) *Qualitative research for allied health professionals: challenging choices*. Chichester, John Wiley & Sons Limited, 3-8

FINLAYSON, Marcia, PREISSNER, Katherine and CHO, Chi (2012). Outcome moderators of a fatigue management program for people with multiple sclerosis. [online]. *American Journal of Occupational Therapy*, 66 (2), 187-197

FUJITA, Daisuke (2010). Using Seating Techniques as a Preventative Measure Against Lower Limb Edema – The Effect of Combining Tilt Angle and Reclining Mechanisms on Wheelchairs. [online]. *Journal of Physical Therapy Science*, 22 (4), 437-441

GREAT BRITAIN, Department of Health (2005). *The National Service Framework for Long-Term Conditions*. [online]. Last accessed 9 January 2015 at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pdf

HARRISON, Sarah (2007). *Fatigue Management for People with Multiple Sclerosis*. [online]. 2nd ed. London, College of Occupational Therapists, Specialist Section – Neurological Practice

HENDRIE, Wendy (2009). *Are you Sitting Comfortably..? A self-help guide to good posture in sitting*. Multiple Sclerosis Trust

HERZBERG, Suzanne R. (1993). Positioning the Nursing Home Resident: An Issue of Quality of Life. [online]. *The American Journal of Occupational Therapy*, 47 (1) – 75-77

LACOSTE, Michele (2003). Powered Tilt/Recline Systems: Why and How are They Used? [online]. *Assistive Technology*, 15, 58-68

LI PI SHAN, Rodney, S. et al. (2012). Reuse and Refurbish: A Cost Savings Delivery Model for Specialized Seating. [online]. *Archives of Physical Medicine and Rehabilitation*, 93 (7), 1286-1288

LONG, David (2014). Posture Management. [online]. In: TAKTAK, Azzam et al. (eds.) *Clinical Engineering: A Handbook for Clinical and Biomedical Engineers*. Oxford, Elsevier Ltd., 285-308

MATHIESON, Cynthia M. (1999). Interviewing the Ill and the Healthy. In: MURRAY, Michael and CHAMBERLAIN, Kerry (eds.). *Qualitative Health Psychology Theories and Methods*. London, Sage Publications, 117-133

MICHAEL, Shona M., PORTER, David and POUNTNEY, Terry (2007). Tilted seat position for non-ambulant individual's with neurological and neuromuscular impairment: a systematic review. [online]. *Clinical Rehabilitation*, 21, 1063-1064

MULTIPLE SCLEROSIS SOCIETY (2009). *Translating the NICE and NSF Guidance into Practice: A Guide for Occupational Therapists*. London, Multiple Sclerosis Trust

NATIONAL PRESSURE ULCER ADVISORY PANEL, EUROPEAN PRESSURE ULCER ADVISORY PANEL and PAN PACIFIC PRESSURE INJURY ALLIANCE (2014). *Prevention and Treatment of Pressure Ulcers: Quick Reference Guide*. [online]. HAESLER, Emily (ed.). Perth, Cambridge Media

NEUMAN, William L. (2014) *Social Research Methods: Qualitative and Quantitative Approaches* [online]. 7th ed. Essex, Pearson Education Limited

PAYNE, Cathy, WIFFEN, Philip J. and MARTIN, Suzanne (2012). Interventions for fatigue and weight loss in adults with advanced progressive illness. [online]. *Cochrane Database of Systematic Reviews*, 1, 1-44

PITTION-VOUYOVITCH, Sophie et al. (2006). Fatigue in multiple sclerosis is related to disability, depression and quality of life. [online]. *Journal of the Neurological Sciences*, 243, 39 – 45

PRINGLE et al. (2011). Interpretative Phenomenological Analysis: a discussion and critique. [online]. *Nurse Researcher*, 18 (3), 20-24

RADLEY, Alan (1999), Social Realms and the Qualities of Illness Experience. In: MURRAY, Michael and CHAMBERLAIN, Kerry (eds.). *Qualitative Health Psychology Theories and Methods*. London, Sage Publications, 16-30

REID, Denise, BRAULT, Richard and CROTEAU, Dianne (2009). Design and development of the two-plane seating concept to enable quality of sitting posture and enhanced occupational performance. [online]. *Technology and Disability*, 21, 149-158

SHANKAR, Sneha, MORTENSON, W. Ben and WALLACE, Justin (2015). Taking Control: An Exploratory Study of the use of Tilt-in-Space Wheelchairs in Residential Care. [online]. *American Journal of Occupational Therapy*, 69 (2), 1-8

SMITH, Jonathan A., FLOWERS, Paul and LARKIN, Michael (2009). *Interpretative Phenomenological Analysis: Theory, Method & Research*. London, Sage Publications

SMITH, Jonathan A., JARMAN, Maria and OSBORN, Mike (1999). Doing Interpretative Phenomenological Analysis. In: MURRAY, Michael and CHAMBERLAIN, Kerry (eds.). *Qualitative Health Psychology Theories and Methods*. London, Sage Publications, 218-240

SMITH, Jonathon A. and OSBORN, Mike (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. [online]. *Psychology and Health*, 22 (5), 517-534

SONENBLUM, Sharon, E. and SPRIGLE, Stephen (2011a). The impact of tilting on blood flow and localized tissue loading. [online]. *Journal of Tissue Viability*, 20, 3-13

SONENBLUM, Sharon, E. and SPRIGLE, Stephen (2011b). Distinct Tilting Behaviours with power tilt-in-space systems. [online]. *Disability & Rehabilitation: Assistive Technology*, 6 (6), 526-535

SPRIGLE, Stephen, MAURER, Christine and SORENBLUM, Sharon (2010). Load Redistribution in Variable Position Wheelchairs in People with Spinal Cord Injury. [online]. *The Journal of Spinal Cord Injury*, 33 (1), 58-64

STEWART, C. P. U. (1991). Physiological Considerations in Seating. [online]. *Prosthetics and Orthotics International*, 15, 193-198

TIERNEY, Martina (2012). *The Clinician's Seating Handbook*. London, Seating Matters

TIERNEY, Martina (2013). Seating: the importance of assessment and appropriate equipment provision. [online]. *International Journal of Therapy & Rehabilitation: Equipment Services*, 69-72.

TREFLER, Elaine et al. (2004). Outcomes of Wheelchair Systems Intervention With Residents of Long-Term Care Facilities. [online]. *Assistive Technology*, 16 (1), 18-27

Appendix 1

Confirmation of Collaboration

Copied and pasted from email contact with researcher

Hi Hannah,

I am emailing you to confirm that I am happy to collaborate with you for your upcoming dissertation. We have discussed that I can contact patients if required prior to any visits and make you aware of any changes to conditions that could impact on your involvement. I am happy to act as gatekeeper and assist in the identification of potential participants for the study. We have agreed that you can contact me as part of lone working procedures to ensure safety for all parties. If any more information is required please do not hesitate to contact me.

Kind regards

[OT name]

Band 7 Occupational Therapist

[OT address]

Hello Hannah

Sorry for the delay. Yes I am still interested in taking part in your research,

Regards [OT name]

Hi Hannah

I am willing to support you with your dissertation. Sorry for late reply - I have been off sick

Regards

[OT name]

Occupational Therapist

[OT address]

Appendix 2

Introductory Letter for Collaborators

Dear

I am in contact with a student who is currently undertaking a research study that aims to explore the impact of a specialist tilt-in-space seat on a person's quality of life and functional abilities. I believe that you may be suitable to take part in this study.

If you would like to take part in this study, which will consist of taking part in one interview regarding your seating, please contact me using the details below within 2 weeks of receiving this letter.

If you confirm with me that you wish to take part in the study, I will pass on your details to the researcher who will then send you out the official documents relating to the study and further information. I will then not be involved in the research any further and you will be solely in contact with the researcher. I will not be informed of the outcome of your specific involvement which will remain confidential at all times.

You are under no obligation to take part in this research and your service from our therapy team will not be affected by your decision whether to take part or not. If you do not confirm that you are happy to take part you will not be contacted any further regarding the study and your details will not be passed on to the researcher.

If you have any further queries please do not hesitate to contact me and I will get an answer for you from the researcher.

Kind Regards

Name of collaborator

Telephone Number

Mobile Number

Email Address

Appendix 3

Researcher Letter of Invitation

Dear

Thank you for confirming that you may be interested in taking part in my research study. The study aims to explore the impact on functional abilities and quality of life for people who have had a specialist tilt-in-space seat. You have been identified as a person who has received a specialist chair at least three months ago through your community therapy team.

Accompanying this letter is an information sheet, supporting the need for this research. The study will be conducted by a Masters Occupational Therapy student in collaboration with Sheffield Hallam University.

Please read the enclosed information and if you decide that you would like to continue to take part in the study, please complete the slip at the bottom of this letter and return to myself in the pre-paid envelope that is also enclosed. I would be grateful if you wish to continue in this process to send the reply slip back within 2 weeks of your receipt of this letter. Please include your preferred contact method. Please be advised that you can withdraw from the study at any time despite sending back the reply slip.

I will be in contact shortly after the receipt of your reply slip via your preferred contact method to arrange a date to complete the interview. In the meantime if you have any concerns or questions, please do not hesitate to contact me by email at:

Xxxxxxxx

or by telephone at the Faculty of Health and Wellbeing on:

0114 2255564.

Please be advised that this number is not a direct number. If you leave a message with the reception staff, they are aware to forward enquiries directly to the researcher.

Kind Regards

Hannah Shelstone

Dear Hannah

I confirm that I am happy to continue to be involved with your research. I will be happy for you to contact me using my details below to arrange an interview date.

Name (printed) : _____
Home Telephone Number : _____
Mobile Number : _____
Email Address : _____

Signature: _____
(Please identify with a star * your preferred contact method)

Appendix 4



Participant information sheet

Study title:	The Impact of Specialist Seating on a Person's Quality of Life and Functional Abilities
Chief investigator	Hannah Shelstone
Telephone number	

Study Sponsor: Sheffield Hallam University

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

This study is for a Masters level research project conducted by a student at the above named university. The researcher is interested in the experiences of people who have received specialist seating at least three months ago.

Participant name:

You will be given a copy of this information sheet to keep

1. What is the purpose of this study?

The purpose of this study is to investigate the impact of specialist seating on the quality of life and functional abilities for individuals with long term physical conditions. This study is for a Masters dissertation conducted by a student.

2. Why have I been invited?

You have been identified as having a long term physical condition which has required you to receive specialist seating at least three months ago to meet your postural needs or for the management of your condition.

3. Do I have to take part?

No. Your decision to take part in this study is entirely voluntary. You may refuse to participate or you can withdraw from the study at any time. Your refusal to participate or wish to withdraw will not influence in any way your current or potential future medical care.

4. What will happen to me if I take part?

If you participate in the study you will be asked a set of interview questions by the researcher in an interview style format, which will be tape recorded for analysis purposes.

5. Expenses and payments

You will not be paid for taking part in this study.

6. What will I have to do?

If you agree to take part in the study we will ask you to answer the questions asked if you feel comfortable to share this information. You have the right to withdraw at any time.

7. What are the possible disadvantages and risks of taking part?

The questions involved in the study are not intended to cause any distress however you may feel upset whilst discussing the effects of your condition. If during the interview you start to feel distressed, the researcher may decide to end the interview. In order to reduce the possibility of bias in the interview, the researcher prefers you to be alone during the interview process. If this is not acceptable to you, a family member or carer may be present but they will be asked to not take part in the interview. You may choose to end the interview at any time without giving a reason. If you begin to feel fatigued during the interview you may request to take a short break at any time, or you can request to re-schedule the interview to a different day. Should you become distressed and feel you need further support following the interview, the researcher can contact your occupational therapist with your consent to arrange further support services.

If as part of the interview you disclose that there is a problem with your chair, you will be advised to contact the manufacturer of your chair, or your occupational therapist.

If you disclose any issues relating to your safety during the interview, the researcher must pass on the disclosure to the relevant Safeguarding Adults Team in the NHS Trust.

8. What are the possible benefits of taking part?

You will be contributing to a body of evidence that is exploring the potential benefits of specialist seating for individuals with a variety of conditions.

9. What if there is a problem or I want to complain?

If you have any queries or questions please contact:

Hannah Shelstone:

xxxxxx

OR

Sheffield Hallam University, Faculty of Health and Wellbeing - 0114 2255564 and leave a message with reception staff

Alternatively, you can contact my supervisor: Melanie Bryer –

xxxxxxx

If you would rather contact an independent person, you can contact Peter Allmark (Chair Faculty Research Ethics Committee)
p.allmark@shu.ac.uk; 0114 225 5727

10. Will my taking part in this study be kept confidential?

The interview will be recorded and then written up word for word. The researcher will check that the recording and the written transcript are the same. She will then erase the recording. The transcript will be kept on a password-protected computer. Identifying details will be taken out of any final report and any publication so people reading these will not be able to identify you. The written transcripts will have all links to you removed at the end of the study and will then be kept for as long as they might be useful in future research. It might be that in the interviews something of concern arises relating to patient care. If that happens, the researcher will consult with her supervisor to discuss what to do. She will act in accordance with her professional Code of Conduct. The documents relating to the administration of this research, such as the consent form you sign to take part, will be kept in a folder called a

site file or project file. This is locked away securely. The folder might be checked by people in authority who want to make sure that researchers are following the correct procedures. These people will not pass on your details to anyone else. The documents will be destroyed seven years after the end of the study.

11. What will happen to the results of the research study?

The results will be written up into a dissertation project. They may be shared at a professional development group linked to the [NHS Trust]. You may request a summary of the results if you take part.

12. Who is sponsoring the study?

The sponsor of the study has the duty to ensure that it runs properly and that it is insured. In this study, the sponsor is Sheffield Hallam University.

13. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and given a favourable opinion by [REC name].

14. Further information and contact details

If you have any queries or questions please contact:

Hannah Shelstone:

xxxxxxx

Sheffield Hallam University, Faculty of Health and Wellbeing - 0114 2255564 and leave a message with reception staff. **Alternatively**, you can contact my supervisor: Melanie Bryer –

xxxxxxxxx

Appendix 5



Participant consent form

Study title:	The Impact of Specialist Seating on a Person's Quality of Life and Functional Abilities
Chief investigator	Hannah Shelstone
Telephone number	

Participant name	<div style="border: 1px solid black; height: 40px; width: 500px;"></div>
------------------	--------------------------------------------------------------------------

	Please read the following statements and put your initials in the box to show that you have read and understood them and that you agree with them	Please initial each box
1	I confirm that I have read and understood the information sheet dated Oct 15 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<div style="border: 1px solid black; height: 40px; width: 150px;"></div>
2	I understand that my involvement in this study is voluntary and that I am free to withdraw at any time, without give any reason and without my medical care or legal rights being affected.	<div style="border: 1px solid black; height: 40px; width: 150px;"></div>
3	I understand that relevant sections of my medical notes and data collected during the study may be looked at by responsible individuals from the Sponsor, the Research Ethics Committee and from the NHS Trust, where it is relevant to this research. I give permission for these individuals to have access to my records.	<div style="border: 1px solid black; height: 40px; width: 150px;"></div>
4	I agree that the researcher may use direct quotations from myself, where appropriate, in the final write-up of the research. I understand that any use of such quotes will be anonymised and will not allow anybody else to identify me.	<div style="border: 1px solid black; height: 40px; width: 150px;"></div>
5	I agree to take part in this study.	<div style="border: 1px solid black; height: 40px; width: 150px;"></div>

To be filled in by the participant

I agree to take part in the above study

Your name

Date

Signature

To be filled in by the person obtaining consent

I confirm that I have explained the nature, purposes and possible effects of this research study to the person whose name is printed above.

Name of investigator

Date

Signature

Filing instructions

- 1 copy to the participant
- 1 original in the Project or Site file
- 1 copy in the medical notes (if applicable)

Appendix 6

Interview Schedule

Opening Questions

- How long have you had your chair now?
- Can you tell me a bit about how you have been getting on with it?
- What made you decide at that point to get the chair?
 - *Can you tell me about the kind of problems you were having that made you make the decision?*
 - *How long had you been experiencing these problems?*
 - *What seating were you using before? How was that impacting on your life?*

The Chair

- Can you tell me about how they made your chair uniquely for you?
 - *Was there pressure care added in?*
 - *How was the chair made to help your posture? Was anything added or taken away?*
- Can you tell me about the comfort of the chair? How does it compare with the previous chairs you were using?

Physical Health

- Can you tell me about any changes you have noticed in your physical health since using the chair?
 - *Have you noticed any changes in your posture?*
 - *Have you noticed anything about your breathing or digestion?*
- Did you get pressure sores in your previous seating?
 - *Have you noticed any changes with their occurrence with your new chair?*
- Would you say that fatigue was a problem for you before?
 - *Has this changed since you have had the chair?*
- Have you noticed any changes in your pain levels since receiving the chair?

Quality of life/Function

- Can you explain how the changes you have told me about have impacted on your life?
 - *(Return back to answers regarding posture, fatigue, pain, pressure care)*
- Has the way you are positioned changed the way you are able to do anything?
 - *Is there anything you are able to do now that you could not do before, or that has become easier since receiving your chair?*
- Have the changes you have experienced impacted on your family members/carers in any way?
 - *Do you feel your relationships with those people have changed in any way?*
- What has been the biggest impact on your life that you have noticed?
 - *What would you say was the best thing about having the chair?*
 - *How do you feel now about the problems you were having before you had the chair?*

Closing

- Is there anything else you would like to say about your chair? Have you found it easy to use for example?
- To wrap us, what would you say has been the best bit about getting your chair?
- Have you got any further questions for me?

Questions in italics relate to appropriate sub questions to use depending on the answers given to the main questions to explore the issues further. If the respondent covers the information in their initial responses the sub questions will not be asked. Other clarifying questions may be asked depending on answers.

Appendix 7

Confirmation From SHU Dissertation Management Group

**Sheffield
Hallam
University**

Dissertation Management Group
F407 Robert Winston Building
Collegiate Crescent, Sheffield S10 2 BP

Direct Line: 0114 225 4380

20 March 2015

HANNAH SHELSTONE

[REDACTED]
[REDACTED]
[REDACTED]

Dear Hannah

**DISSERTATION MANAGEMENT GROUP
AND INDEPENDENT SCIENTIFIC REVIEW**

Your dissertation proposal was independently reviewed by two members of the Dissertation Management Group (DMG) on 2 February 2015. Your proposal was approved by the DMG and was also granted ethical approval on behalf of the Faculty of Health and Wellbeing Ethics Review Group.

Both reviewers made a number of suggestions to improve your proposal. The DMG has now been informed by your reviewer, Colette Fegan, that these amendments have been made.

You may now begin your research.








Yours sincerely

Paula Vinicombe

On behalf of the Dissertation Management Group
and the Faculty of Health and Wellbeing Ethics Group

Appendix 8

NHS Research Ethical Committee Provisional Decision


Health Research Authority





Telephone: 

03 July 2015

Miss Hannah Shelstone
Student - MSc Occupational Therapy
Sheffield University
c/o Melanie Bryer
Robert Winston Building
Broomhall Road
S10 2DN

Dear Miss Shelstone

Study Title:	The Impact of Specialist Seating on a Person's Quality of Life and Functional Abilities
REC reference:	15/YH/0290
Protocol number:	N/A
IRAS project ID:	180587

The Research Ethics Committee reviewed the above application at the meeting held on 25 June 2015. Thank you and Ms Bryer for attending to discuss the application.

Provisional opinion

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

- 1 Consideration to be given to increasing the number of participants in the study to 8 or 10 to ensure that saturation is not reached.

A Research Ethics Committee established by the Health Research Authority

- 2 An opt-in approach must be used for the study and no cold-calling to take place. Potential participants must be able to decide themselves whether to take part in the study and then make contact through the therapist in the first instance who would then contact the applicant.
- 3 The process if any safeguarding issues are disclosed by participants is requested. The Participant Information Sheet must contain details that if any of these issues are disclosed they would be brought to the attention of the Safeguarding Adults Team.
- 4 Confirmation that participants will be told that if they suffer from fatigue as a result of participation in the study, the study can be re-scheduled or a break taken. This information will also need to be included in the Participant Information Sheet.
- 5 The data which will be digitally taped must be physically destroyed and the use of an SD card is advised for this purpose.
- 6 The study must be registered on a publicly accessible database, is Trust, University database or searchable webpage.
- 7 The Participant Information Sheet would need the word 'No..' including at the start of the section 'Do I have to take part?'.
- 8 The Consent Form to include a statement that quotes may be used.
- 9 Confirmation is required that the student has appropriate training in assessing a participant's capacity and support.
- 10 The definitive interview questions would need to be submitted, not just draft questions.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact [REDACTED] [REDACTED] REC Manager, in the first instance.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. A step-by-step guide on submitting your response to the REC provisional opinion is available on the HRA website using the following link:
<http://www.hra.nhs.uk/nhs-research-ethics-committee-rec-submitting-response-provisional-opinion/>

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 02 August 2015.

Summary of the discussion at the meeting

Ms Byer and you joined the meeting for discussion.

A Research Ethics Committee established by the Health Research Authority

Social or scientific value; scientific design and conduct of the study

Members stated that the proposal did not identify the gap in the current evidence base so justification for the research was not clear.

You stated that literature searches had shown studies into pressure and physical symptoms but you were interested in how these affected a person's quality of life, ie ease, others having to help. You stated that you were wishing to look at the holistic view.

Members stated that the number of the participants for the study, 6, was low for the applicant may reach data saturation.

You stated that the University had advised you to use this number and you had limited time to do the data analysis.

Member suggested using 8 or 10 participants and then an amendment would not need to be undertaken to increase the numbers.

You acknowledged this point.

Members enquired whether there was any suitable Patient and Public Involvement Group within routine care.

You stated that there was not.

Recruitment arrangements and access to health information, and fair participant selection

Members stated that the recruitment process was not clear and an opt-in process had not been used.

You stated that this issue had been raised by the University Dissertation Group. You stated that the study was time limited and it would be easier for you to send the letter as you needed participants for her study. You confirmed that the Therapist would let the patient know that the letter would be arriving.

Members queried how the applicant would have the participant's name and address.

You stated that the therapists act as the gatekeepers and would identify and send the letters for her. You confirmed that if you did not hear back from the participant, you would remove their name and address.

Members stated that an opt-in approach must be used for the study and no cold-calling to take place. Members stated that potential participants must be able to decide themselves whether to take part in the study and then make contact. Members agreed that the initial contact must be through the therapist who would then contact the applicant.

You accepted this point.

You enquired whether the therapist could send the Participant Information Sheet out to potential participants.

Members stated that this process would be acceptable.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

Members enquired the process if any safeguarding issues were disclosed by participants.

You agreed to respond to the Committee after the meeting.

Members confirmed that the Participant Information Sheet must contain details that any safeguarding issues disclosed would be brought to the attention of the Safeguarding Adults Team.

You accepted this point.

Members enquired whether the applicant thought that participants may have fatigue as a result of participation in the study and what assessments would be undertaken to assess this possibility.

You acknowledged this and confirmed that you would ensure that participants were happy to continue by asking them.

Members confirmed that the Participant Information Sheet must clearly make participants aware that a break or re-scheduling can be taken if required.

You agreed to this point.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

Members enquired whether the tapes used would be audio or digital.

You confirmed that digital tapes would be used.

Members confirmed that the data is physically destroyed and the use of an SD card is advised.

You agreed to this.

Members stated that the study must be registered on a publicly accessible database, i.e. a publicly accessible Trust or University web page.

You agreed to this.

Informed consent process and the adequacy and completeness of participant information

Members queried whether quotes would be used in the results of the study and if so, a statement included on the Consent Form included.

You stated that you may use quotes and would amend the Consent Form accordingly.

Suitability of the applicant and supporting staff

Members enquired whether you had any formal training on adults lacking capacity.

You stated that you had received on the job training in this area. Ms Bryer confirmed that the applicant has an experienced module leader and there was online training within the module.

Members informed you that confirmation would be required that appropriate training on assessing a potential participant's capacity to participate in research had been received and support would be available.

You accepted this point.

Suitability of supporting information

Members confirmed that the definitive interview questions would need to be submitted to the Committee.

You agreed to submit this.

Ms Bryer and you left the meeting.

Documents reviewed

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		
Interview schedules or topic guides for participants [Example interview questions]	2	13 January 2015
IRAS Checklist XML [Checklist_09062015]		09 June 2015
Letters of invitation to participant [Researcher letter of invitation]	1	16 March 2015
Letters of invitation to participant [Collaborator introduction letter]	1	16 March 2015
Participant consent form [Consent Form]	1	14 January 2015
Participant information sheet (PIS) [Participant Information Sheet]	2	14 January 2015
REC Application Form [REC_Form_09062015]		09 June 2015
Referee's report or other scientific critique report [Letter of approval from DMG]	1	20 March 2015
Research protocol or project proposal [Proposal form]	2	16 March 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	03 June 2015
Summary CV for student [Student CV]	1	28 April 2015

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached

sheet

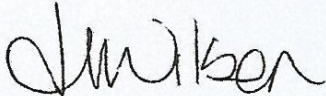
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

15/YH/0290

Please quote this number on all correspondence

Yours sincerely



pp



Chair

Email: 

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Mr Brian Littlejohn

Ms Melanie Bryer, Sheffield Hallam University



Appendix 9

Covering letter to Ethical Committee Addressing Required Amendments

5th August 2015

To Whom it May Concern:

REC Reference: 15/YH/0290

IRAS Project ID: 180587

Study Title: The Impact of Specialist Seating on a Person's Quality of Life and Functional Abilities

Please find below the responses to the points raised at the Research Ethics Committee meeting in your letter of 3rd July 2015.

1. Number of participants has been raised to 10 as per suggestion
2. Documentation and procedure has been changed to ensure that potential participants contact the therapist collaborator first to confirm they would like to be contacted by the researcher. Only the details of those who get back in touch with the collaborator will be passed on to the researcher.
3. Participant Information Sheet altered to reflect the fact that if any safeguarding issues are disclosed during the interviews, the researcher is obligated to pass on information to the Safeguarding Adults Team within the NHS Trust. This will be done with the support of the therapist collaborators who are part of their care team (unless concerns are relating to them) and the support of the researcher's academic supervisor (who is acting as chief investigator).
4. Participant Information Sheet updated to reflect the fact that it will be made clear to participants that small breaks may be taken if they experience fatigue during the course of the interview at any time. It also states that the rest of the interview can be rescheduled to another convenient day should the participant be too fatigued to continue.
5. The digital audio recorder available to loan from the university for the duration of the study plugs directly into the computer to allow transfer of audio files. The technicians in the university have confirmed that once the files are deleted, either on the computer or on the recorder itself, this is permanent and they cannot be recovered. Due to the study not being funded it is not practical for the researcher to purchase an audio recorder with an SD card due to the expense.

6. Through SHURA (Sheffield Hallam University Research Archive: (below is taken from the univeristy's open access publication policy)
“The University is committed to making the outputs of its research as widely available as possible and supports the principles of open access to make the outputs of publicly-funded research available through unrestricted online access. The policy and associated procedures apply to all research outputs produced by University staff in the course of their employment and by postgraduate research students for the duration on their studies at the University. The policy applies to all types of research irrespective of the source of funding but acknowledges that there may be individual conditions/circumstances such as confidentiality or commercial sponsorship which need to be considered before making a work open access. A record for each research output resulting from research carried out by University researchers must be added to the institutional research output repository, SHURA (Sheffield Hallam University Research Archive). Authors must at the same time or as soon as possible afterwards deposit a copy of their work in SHURA. This will be made open access/publicly available in accordance with their agreement with the publisher and with the publisher's open access policy.”
<http://www.shu.ac.uk/research/ethics/open-access-publication.html>
7. Participant Information Sheet has word ‘No’ added in as advised
8. Consent Form updated as advised
9. Due to utilising gatekeepers to identify participants they will only identify people who meet the inclusion criteria - i.e. only those who have been deemed to have capacity. The qualified OTs have the relevant experience and training to assess a person's capacity, the researcher will not be assessing participant capacity. Due to the participant involvement being one interview only and only over a short time period from recruitment to interview, continued capacity will not need to be monitored and this is unlikely to change.
10. Interview schedule submitted as requested.


I hope this sufficiently clarifies the issues raised and I look forward to hearing from you regarding the progress of the study.

Kind Regards

Hannah Shelstone

Appendix 10

NHS Research Ethical Committee Final Approval


Health Research Authority
NRES Committee [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
Telephone: [REDACTED]

21 August 2015

Miss Hannah Shelstone
Student - MSc Occupational Therapy
Sheffield University
c/o Melanie Bryer
Robert Winston Building
Broomhall Road
Sheffield
S10 2DN

Dear Miss Shelstone

Study title: The Impact of Specialist Seating on a Person's Quality of Life and Functional Abilities
REC reference: 15/YH/0290
Protocol number: N/A
IRAS project ID: 180587

Thank you for your letter of 5 August 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, [REDACTED].

[REDACTED] Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **Favourable** ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

A Research Ethics Committee established by the Health Research Authority

Hannah Shelstone 23038436

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non-registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to ^{*} management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [REC Response]	1	05 August 2015
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)		
Interview schedules or topic guides for participants [Example interview questions]	3	27 July 2015
Letters of invitation to participant [Researcher letter of invitation]	2	16 July 2015
Letters of invitation to participant [Collaborator introduction letter]	2	16 July 2015
Participant consent form [Consent Form]	2	16 July 2015
Participant information sheet (PIS) [Participant Information Sheet]	3	26 July 2015

A Research Ethics Committee established by the Health Research Authority

REC Application Form [REC_Form_09062015]		09 June 2015
Referee's report or other scientific critique report [Letter of approval from DMG]	1	20 March 2015
Research protocol or project proposal [Proposal form]	3	26 July 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	03 June 2015
Summary CV for student [Student CV]	1	28 April 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

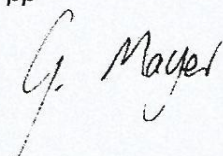
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/YH/0290	Please quote this number on all correspondence
-------------------	-------------------------------------------------------

With the Committee's best wishes for the success of this project.

Yours sincerely
pp



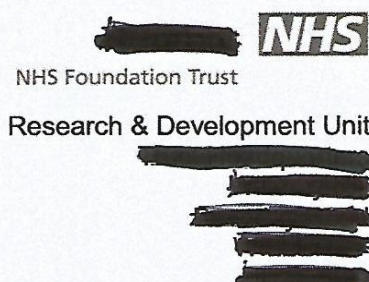
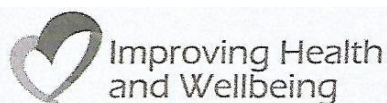
Dr [REDACTED]
Chair

Email: [hrescommittee@\[REDACTED\]](mailto:hrescommittee@[REDACTED])

A Research Ethics Committee established by the Health Research Authority

Appendix 11

NHS Research and Development Approval



16/09/2015

Hannah Shelstone
Robert Winston Building,
Sheffield Hallam University
Broomhall Road
Sheffield
S10 2DN

Dear Hannah Shelstone

Re: R&D N°: 15/07/655

REC N°: 15/YH/0290

IRAS N°: 180587

The Impact of Specialist Seating on Quality of Life and Function

I am pleased to notify you formally that NHS permission for research has been granted for this study by [redacted]

Date of commencement of NHS permission for research: 16/09/2015

We request that you complete the attached spreadsheet on a weekly basis and email to [redacted]@nhs.net.

NHS permission for the above research has been granted on the basis of the documentation submitted to the R&D Unit.

Indemnity for this study is provided by the Sheffield Hallam University.

[redacted] Trust conducts all research in accordance with the requirements of the Health Research Authority (HRA), Research Governance Framework, NHS policies and R&D standard operating procedures. In undertaking this study you agree to comply with all reporting requirements and systems put in place by the Trust to deliver research governance.

Please note - you must ensure that the protocol is followed at all times. Should you need to amend the protocol, please follow HRA procedures. You should forward a copy of all amended documentation together with written confirmation that a favourable opinion has been given by the HRA, to the R&D Unit at the trust, and confirmation that there has been no change in the NHS permission status should be obtained prior to further research activity commencing.

I would like to wish you every success with this study.

Yours sincerely,

[redacted]